



**Developing
Meaningful
Connections
with People
with
Dementia**



*A Training
Manual*

Editors:

Beth Spencer
Anne Robinson
Chris Curtin

Contributors:

Roxanne Chang
Lynn LaRue Chenoweth
Regina McClurg
Shelly E. Weaverdyck
Laurie White
Jayne Yatzak
Jitka Zgola

Jo Campbell, Gwyn Gardner, Barbara Kendall, Anne Remley, Jim Wealton

Cover Photos: Silver Club Staff Members Patricia Hall and Beth Carlson with Silver Club Members, University of Michigan, Ann Arbor, Michigan

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Editors

Beth Spencer, LMSW, MA, has worked in the dementia care field for more than 25 years in a variety of capacities, including care management, counseling, teaching, and training. As a trainer and educator, Beth has worked in many settings from universities to long-term care and has been a keynote speaker at many Alzheimer's Association annual conferences. She is currently director of Silver Club Programs for adults with memory loss at the University of Michigan Health System. She is co-author of the handbook, *Understanding Difficult Behaviors*, with Anne Robinson and Laurie White and also of *Moving a Relative with Memory Loss* with Laurie White. elizspen@umich.edu

Anne Robinson, MA, has worked in the field of dementia care for more than 25 years as an educator, trainer, consultant, and group work specialist in residential and community-based programs. She founded and directed the Alzheimer's Education Program at Eastern Michigan University for 16 years. Currently she is Executive Director of Optimal Life Designs in Dementia Care, a non-profit organization that specializes in providing cutting-edge quality education and resource materials in dementia care for healthcare professionals. Her organization sponsors the Annual Edna Gates Conference on Dementia Care and the Lillian & James Portman Conference for Direct Care Workers. Contact Information: Optimal Life Designs in Dementia Care, P.O. Box 128, Hamburg, Michigan 48139 Telephone: 810.231.2723 Fax: 810.231.2743 E-mail: annerobinson2@sbcglobal.net

Chris Curtin, B.A. RN,C a Certified Gerontological Nurse is an independent consultant and trainer. She has been training direct care workers for 20 years. Chris is the President of Community Services Network (CSN) in Traverse City, MI. CSN is a 501(c)3 organization

that trains direct care workers in all settings. Chris can be reached by email ccurtin@voyager.net or by phone 231-536-0483.

Contributors

Roxanne J. Chang, JD, MS LLP, elder law attorney and limited licensed psychologist in Plymouth, Michigan, with a focus on issues regarding individuals with dementia, as well as a consultant for Optimal Life Designs in Dementia Care. roxjchang@yahoo.com

Lynn LaRue Chenoweth, MT-BC, NMT Fellow, is a board certified music therapist specializing in dementia care and aphasia and gait rehabilitation. Director of Music Therapy, Rehabilitation Services, Ann Arbor, MI.

Regina McClurg, LMSW, Director, Apogee Training and Consultation Services and a trainer for Gerontology Network Services, Grand Rapids, Michigan.

Shelly E. Weaverdyck, PhD, Director Eastern Michigan University's Alzheimer's Education and Research Program, and Private Consultant in Ann Arbor, Michigan. sweaverd@umich.edu.

Laurie White, MSW, owner of Dementia Care Consulting in Santa Rosa, California, providing clinical services to families and conducting dementia care training programs around the country. Laurie@dementiaconsulting.com.

Jane Yateczak, M.S., OTR/L, Botsford Hospital, Geropsychiatric Services; Eastern Michigan University, Gerontology Program.

Jitka Zgola, OT(C), occupational, therapist, educator, and advisor to caregivers of people with dementia. As an author of two well-received books in dementia care, she is a much sought after speaker in Canada, the US, and Europe.

Other contributors include **Jo Campbell**, M.A., Alzheimer's Education Program, Eastern Michigan University; contact Jo at 734-546-5515. **Gwyn Gardner**, former staff member of EMU's Alzheimer's Education Program. **Barbara Kendall**, retired public health nurse from Michigan's Upper Peninsula. **Jim Wealton**, a social worker at Pathways Community Mental Health in Marquette, Michigan, with several decades of training and consulting experience in mental health and nursing homes. **Anne Remley**, the daughter of Dorothy Luther and an original Huron Woods family member.

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This dementia manual is being produced at an exciting time in Michigan. In 2006, the Dementia Coalition published the *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers*. It is a guide meant to help direct care workers identify the knowledge and skills needed for providing optimal dementia care. The guide identifies seven domains of competency that are important when providing care to people with cognitive impairments. This manual, *Developing Meaningful Connections with People with Dementia*, provides a foundation for training in dementia that addresses all of the competencies.

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of the content for this train-the-trainer manual was shaped from early experiences and lessons learned from two innovative residential demonstration projects that we were privileged to be part of. Wesley Hall, an eleven bed unit originally located on the campus of the United Methodist Retirement Community (now the Chelsea Retirement Community), was created in the 1980s. The original Huron Woods, a thirteen bed residential dementia program located on the campus of St. Joseph Mercy Health System in Ann Arbor, was established in 1990. It provided us with a unique opportunity to learn about the challenges of developing an "aging in place" program for individuals with moderate to late stage dementia. These demonstration projects were instrumental in helping us to identify and evaluate the key elements of optimal dementia care. They also enabled us to pilot and evaluate training programs for both professionals and paraprofessionals on a variety of dementia topics.

We are deeply grateful to the residents, their families and the staff of the original Huron Woods Project who supported our work. Our lives have been enriched immeasurably by their courage, sensitivity and humanity. Their voices need to be heard.

Thanks to the various organizations who have contributed to or given us permission to use their materials. And thanks to the Michigan Dementia Coalition for allowing us to include a copy of the Dementia Competencies document in this publication.

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Beth Spencer
Anne Robinson
Chris Curtin

How to Use This Manual

A Word about Format

Issues to Consider in Training Staff, the first section in this manual, is background reading for you, the trainer. It highlights adult learning principals and other concerns that may be important for you to consider as you do dementia training.

There are nine general sessions in this training manual. Each session consists of many ideas that may be used for multiple trainings on that particular topic. Each session is divided into parts.

In print:

- ***Suggestions for Trainers*** are just that – some of our thoughts, ideas, and suggestions for ways of putting material together for that topic area. In the *Suggestions* sections, we offer ideas of videotapes to use, additional reading, some of our beliefs and ideas about that particular area, and training tips for using the exercises and case studies. At the end of each *Suggestions* section is a list of the materials on the CD for that session.
- ***Outline for Trainers***. Each session has an *Outline* written for the trainer. There may be more material than you want, or you may find there is enough information for multiple sessions. Feel free to use it as you wish.
- **Reference List**. All references throughout the manual are included on this general list at the back.
- **Audiovisual Resources**. All AV resources throughout the manual are included with source information at the back.
- **Dementia Competencies, Michigan Dementia Coalition**. These are available on-line but are reprinted here for your convenience.

On the CD:

- **Handouts, Exercises, Case Studies**. Depending on the topic area, there are handouts and various kinds of exercises to use in training. All handouts, exercises and case studies are on the CD. These are for you to duplicate and use with staff.
- **Photographs**. Some sessions include photographs of people or objects. These can be found on the CD and are available for printing or duplication.
- **Powerpoints**. Most sessions include powerpoint slides designed to follow the *Outline for Trainers*.

On the DVD:

- **Videotape clips**. All videotape footage is on the DVD.

Issues to Consider in Training Staff

Beth Spencer and Regina McClurg

This chapter is a reminder about some of the issues that are important to ensure effective and successful training.

Remember: better trained staff will provide better care, will be more confident and happier in their jobs, and often will lead to lower turnover. “Our research indicates the best weapon against turnover is continuing education that specifically deals with the interpersonal aspects of resident care.” (p. 84, Pillemer, 1996)

In this chapter we will discuss briefly the following issues:

- Obstacles to effective staff training
- Picking up the challenge: Overcoming obstacles to staff training
- Basic adult learning principles to keep in mind
- Goals of effective dementia training
- Effective and interactive training strategies

Obstacles to Effective Staff Training

Of course, the obstacles to effective training are different in every setting. But there are some that are common to trainers in nursing homes, assisted living, and adult day programs. It can be helpful to list the barriers that you face, to begin to understand what you have control over and what you don't.

• **Institutional attitudes toward direct care staff.** In all of the settings where we work, there are institutional attitudes toward staff that may affect the way we feel, the way staff feel, and the way that training is viewed. Often these attitudes are unspoken, unconscious, and go

unchallenged. Examples include nursing homes where the relationship between administration and direct care staff is suspicious or even openly antagonistic. In some facilities there is not antagonism, but there is no support either. There may be little funding available for training and no attempt to make staff feel good about their jobs. In other homes, there are attitudes of respect among all levels of staff, who view each other as crucial parts of the team. No matter where your program falls on this continuum, these attitudes will have an impact on your training program.

• **Institutional attitudes toward training.** Is training viewed as a necessary evil in your facility? Or as a crucial, on-going activity? Again, where your program falls on this continuum will have a profound impact on you as trainer. Some of the factors that may be telling include:

- whether staff are willingly freed up for regular trainings
- whether problem-solving sessions or staff team meetings are viewed as a legitimate use of time
- whether you are given the resources you need for effective training
- whether you are able to provide refreshments for staff during training (at the facility's expense) and generally make staff comfortable.

• **Attitudes of staff toward training.** This will be partially determined by the attitude of the institution toward training. If the administration views training as a necessary evil, and staff have to work extra hard to make up the time missed, staff attitudes toward training will necessarily be negative. Are trainings mandatory? Are staff paid for training time? Do they have to take on extra work as a result? All of these will affect staff attitudes.

• **Previous experiences with training or education.** Many of the people who are direct care staff in our programs had

negative or difficult experiences in school when they were younger. They may associate classroom time with testing, failing, or being put on the spot. Also they may not always see the association between training topics and the realities of their jobs.

- **A training style that does not match the learning styles of staff.** Later in this chapter we discuss some things to keep in mind about adult learners. If we, as trainers, go in and lecture for forty-five minutes, we will lose the attention of many adult learners.

- **Tired and distracted staff.** Unfortunately it is a fact of life that many of the staff we hire and work with have difficult lives. Often we know nothing about all the other things going on in people's lives, or we may be aware of them but feel helpless. It is not unusual for staff to be dealing with eldercare issues at home, with substance abuse problems, crime, children with problems, illness or death, with financial crises, or to be single parents raising children under difficult circumstances. These concerns can cause enormous distraction for staff members that will make training more of a challenge.

- **Turnover.** One of the difficult facts of life in the world of long term care is that staff turnover is a reality of life (particularly in times of low unemployment). For trainers this is a continuing challenge – how to structure training for a revolving-door staff.

Picking up the Challenge: Overcoming Obstacles to Staff Training

- **Just listing the obstacles where you work can be a helpful exercise.** The list above is by no means exhaustive. Some of those may not apply to your situation at all. But

none of us works in a perfect environment; there will always be some barriers to training, and it is helpful just to be aware of them.

- **Know what you do and do not have control over!** Some of the barriers in your place of work may be things that you cannot change. Again, it is helpful to be aware of these so you do not constantly feel that you are knocking your head against brick walls. Working for change on things we can change, letting go of that we cannot change are skills we all need to cultivate.

- **Think about how to build support for training with administration.** If training is not viewed as important, are there things you can do to help change that attitude? Can you train staff about a particular kind of problem and demonstrate change in the quality of care? If you are excited about specialized training, can you get permission for a special series?

- **One of the things you can change is your training style.** If your staff are not responsive, remain aloof and unengaged, look at your training style. Are you drawing on their experience and expertise? Are you using the interactive strategies that work best with most adult learners?

- **Don't ask staff to do the impossible.** Many of us have a vision of what ideal dementia care should look like. But most of us work in less than ideal settings, often short-staffed. If we train staff to provide care in ways that may be impossible given their work environment, we are doing them a disservice, and they will quickly become disenchanted with training.

- **How are staff supported in your environment?** Perhaps there are things that you or a staff team can do to help staff with stressful lives feel more supported.

Basic Adult Learning Principles to Keep in Mind

- **Adults must see the need to learn.** Therefore, **information should be practical.** If, as trainers, we can constantly relate the content of what we are teaching to staff jobs and to our residents or clients, it will immediately be more relevant.

Example: When teaching about the symptoms of dementia, use residents from your program to illustrate different aspects of dementia.

- **Adult learning is usually seen as a means to an end** rather than as an end in itself. Focus on how staff can use the information; avoid being too theoretical or impractical.

Example: Learning about ways to avoid difficult behaviors will make staff tasks easier and less stressful.

- **Adults have a variety of learning styles** – visual, auditory, and kinesthetic (motor learning, learning by doing). By a large majority, most adults are primarily visual learners. Thus it is very important to vary how we present material.

Example: We often present mini-lectures accompanied by handouts or powerpoints or both, so that staff are hearing and seeing at the same time. We also use lots of case studies and exercises to have them practice and think about what they are learning. And we use a lot of discussion to draw out and build on their experience.

- **Enhancing self-esteem is a strong reinforcer** for learning. Many staff have experienced education as an atmosphere of failure. Focusing on staff strengths and accomplishments will motivate staff to be involved in training.

- **Adults are more likely to let mistakes affect their self-esteem** than younger learners. Again, it is imperative to make the training environment a safe place,

where staff do not feel they are being set up for failure.

- **Adults need to integrate new learning into what they already know.** Whenever possible, build their experiences into the training; this reinforces the importance of their experience and helps them put new ideas in context. We have included discussion questions at some points that build on their experience.

Example: When training staff about families, draw on the experiences of those who have had a family member with dementia. What was it like for them? What might it be like for other staff members to have someone in their family diagnosed with Alzheimer's disease?

- **Information that conflicts with current beliefs or values will be more difficult (or impossible) for staff to learn.** In order to produce behavioral change, learning must impact feelings, beliefs, and values. But this kind of learning takes more time, and requires us to be patient and non-judgmental. It is imperative that we do not imply that staff values are wrong; rather we must try to help them see other points of view.

Example: Many staff believe that difficult individuals with dementia are intentionally resistant or combative. Teaching them about the changes in the brain, and the course of Alzheimer's disease may help combat this belief, but it will take time and repeated reinforcement.

Example: We all hold strong values about families and how they "should" behave. Many times what staff see in families of residents conflicts with their values about what families "should" do. Helping them begin to understand their own value systems, and to empathize with families who come from different experiences can help begin to change attitudes. However, it will not be easy!

- **Fast-paced, complex, or unusual learning tasks may interfere with learning.**

Choose activities with which staff will be comfortable, and break complex tasks into simple steps for learning.

- **Adults like to know what they will be learning.** Clarifying goals, expectations, and the agenda at the beginning helps most adults feel more comfortable.

- **Adult attention spans are often about 15-20 minutes.** It is helpful to plan to change your mode of presentation about every fifteen minutes.

Example: In a forty-five minute training, you might want to include a mini-lecture, brainstorming, and a five minute clip from a videotape.

- **It is important to reinforce “minority” opinions** and the fact that there are generally multiple ways of approaching any situation. This can help dispel resistance among staff, teach tolerance, and reinforce a creative, less judgmental approach to problems.

Example: Most of the staff believed that Mrs. Jones’ combativeness was due to a long-standing “ornery” personality problem, which her daughter confirmed. Two staff, however, wondered whether she became combative when she was frightened. The trainer reinforced that as another possible factor and led a discussion about what staff could do to help her feel more secure if, indeed, she is frightened.

- **Adult learners learn better when they can readily apply the information.** To help them integrate new materials and approaches, it is important to help them identify ways they can apply them.

- Focus on how the discussion applies to their lives and jobs.
- Present some sample situations where they can apply what they have learned.
- Ask them how they can apply it.

- Assign some homework to do before the next training session.

- *Example:* At the end of a communication training session, we asked staff to come to the next session prepared to describe one conversation with a resident that went well, and one that did not go so well.

- **Adults learn better in a comfortable environment.** We are all influenced to greater and lesser extents by our environments. If training occurs in a dismal, uncomfortable room, staff are sure to be less responsive. Can you do anything to improve the training environment? Can you provide snacks or drinks? Food always helps create a more pleasant atmosphere!

Goals of Effective Dementia Training

We have listed goals for each of the training sessions. However, your goals may be somewhat different. It is helpful to step back before a training session and think about the most basic ideas you hope staff will leave with.

Our most basic goals in all dementia training we do are the following:

- To help staff understand that first and foremost, this **resident is a person**, who happens to have a disease. Throughout all sessions we emphasize that in different ways, which are described in *Respecting the Humanity of the Person*. We try to keep this goal in our minds at all times, as we are training staff.

- To help staff understand that the changes they see, the behaviors they struggle with, are largely the **result of a brain disease** that the person has no control over.

- To help staff understand that **behaviors have meaning** – that they are sometimes

the only means of communication left to individuals with dementia.

- **To support staff**, to enhance their self-esteem whenever possible, by involving them as peers and teammates in learning about dementia, as they perform difficult, but often rewarding, jobs.

Effective and Interactive Training Strategies

As discussed above, adults generally learn and retain information better when they are actively involved in the process, not just passive listeners. The following are some of the many training techniques available to help engage your staff.

- **Brainstorming** is a technique for getting participants involved in the discussion quickly. In a brainstorming session, the trainer asks a general discussion question to get people thinking. It is a good way to show staff that you are interested in their thoughts and ideas. It is important for you to think through ahead of time what answers you hope to get, what points you wish to cover. Throughout this manual we have included discussion questions that we use for brainstorming.

Some rules for brainstorming:

- Use a flip chart or blackboard to write answers to the questions.
- Write everyone's contribution down.
- Try to make a positive comment about each, even if it's simple. Examples: "That's an interesting idea." or "Okay."
- Ask questions if you don't understand what the staff member is saying; try to help her clarify her thought or idea.
- Make it a non-judgmental process – do not allow staff to laugh at each other's comments or whisper about one another. Model the kind of non-judgmental attitude you wish to create in training.

- Use their ideas to illustrate points you want to make. Have examples ready from the residents you work with.
- Go back through the list at the end, highlighting points, or disagreeing with points in a way that corrects but is not judgmental. Example: "This point was an interesting idea; lots of people think it is true about dementia, but in fact it's one of the myths about Alzheimer's disease."
- Add other points at the end that you wish to make, or use transparencies to summarize.

- **Case studies** are short presentations of a situation or a resident with questions for staff to respond to. They are often a good way to illustrate specific ideas you are trying to get across, and a way for staff to practice a particular skill. For example, we often use case studies to help staff think about the causes of particular difficult behaviors, and to practice problem-solving techniques. Throughout this manual we have included samples of case studies that we have used to address different topics.

Some things to think about when designing your own case studies:

- Use situations that are familiar to staff. Building case studies around some of your own residents can help staff view their problems in new ways.
- Use case studies to sensitize staff to the feelings of residents.
- Think carefully about the questions for the case studies. What ideas do you particularly want to get to? Make the questions as specific as possible. *Examples:* What do you think Mr. Brown is feeling? What would you want a staff member to say to you if you were in this situation?

Logistical issues in using case studies:

- Be sure you have enough copies of the case study so everyone can see one.
- Be aware of the literacy level of staff. Always read the case study aloud to

the group before they begin working on it. Ask if it is clear, or if people have questions.

- Think about whether you want staff to work individually on the case study or in small groups. If literacy is an issue, groups will work better. Sometimes it is helpful to have staff think individually about the questions and then discuss them in their groups.
- Keep groups to a maximum of six (three to four is probably preferable).
- Allow enough time for the groups to work through the case study, but circulate to make sure they are doing it.
- Think about how you are going to debrief the case study. Will you talk about it as a whole group? Will you have each group report back? Does each group need to appoint a spokesperson?

• **Videotapes** can be good tools for making information and situations real to staff. However, having staff sit and watch videos for thirty minutes or more is not an effective teaching technique.

To use videotapes most effectively in training, consider the following:

- Always preview tapes prior to showing them. Does this tape convey what you want it to? Are you using it for a specific training purpose or just filling time with it?
- Show only short segments at a time. Anything beyond ten minutes or so will lose some people's attention. Stop at good breaking points and discuss the video before continuing. We sometimes use sixty minute tapes, but break them down into four or five discussion segments. Thus a forty-five minute tape can easily take several hours to show.
- Before you turn the tape on, give staff specific things to look for as they watch. We have made suggestions of discussion questions to use with a number of the

recommended videos. Research has demonstrated that people learn more from audio-visuals when their watching is directed. Give them a brief summary of what they will be seeing and then suggestions about what to watch for.

- Examples: "As you watch this, think about how the elderly woman is feeling." or "Make a list of all the activities staff are doing with residents in this videotape."
- Always allow time for debriefing. Videos have a much more lasting training impact when they have been discussed. Also sometimes staff may be misinterpreting what they see, or there may be something upsetting that should be discussed. Have specific debriefing, discussion questions ready.

• **Use of visuals.** Since most adults are primarily visual learners, it makes sense to include visual reinforcement as much as possible. For most sessions, we have included powerpoints on the CD that follow the outline in the *Outline for Trainers* and many staff handouts. Most adults learn best if they **hear, see, and practice** the material being presented.

• **Role-plays** are a good way of portraying how you do or don't want staff to interact. Generally role-plays are short (two-three minutes) skits that show a situation between people. Using role-plays can be a very effective way of demonstrating communication techniques.

Sample role-plays are included in *Adapting Our Methods of Communication* and in *Helping Staff Understand and Respond to Families*. However, you may want to write your own to address particular issues from your program. Role-plays could address staff-family issues, as well as staff-resident issues.

Some trainers do role-plays that are “ad-lib” with staff members from the audience taking one of the roles. We only recommend that if you and your staff are extremely comfortable together. One of the dangers with ad-lib role-plays is that residents will be reduced to caricatures, instead of presented in a sympathetic manner that staff can learn from. On the other hand, many times staff remember lessons learned in impromptu role-plays long after they may have forgotten other things we said.

Some things to think about in developing role-plays:

- Write out a script of the scenario you wish to demonstrate and find a partner who is willing to role-play in training with you. Be sure you practice it several times, so that you are comfortable doing it in front of staff.
- Be careful not to caricature residents. As mentioned above, one of the dangers of role-plays is that we can easily fall into stereotyping and making fun of residents – the very things we are trying to teach staff not to do!
- Focus staff’s attention (as with videotapes) by asking them to look for very specific things in the role-play.
- *Example:* “As you watch this, think about what the staff member is feeling, and think about what the resident is feeling.”
- **Storytelling.** Stories – of residents or family members or others you have known – can be used to deliver a message or teach a point. Often a story does a better job of making your case or helping staff see the practical application than anything else. Stories are used in conjunction with other forms of learning techniques, such as overheads, lecture, handouts, video, etc. Storytelling is an effective way to communicate because stories are real life experiences that come from working with real people. Audiences like stories because

they are a break from more traditional teaching methods. Stories are informal and can relax your audience, similar to telling a joke to “warm up” the group. Most staff can relate to stories because they all have some of their own and it is a comfortable formula that most of us have grown up with. Stories can be humorous or sad as long as they convey your message in a meaningful and respectful way.

Some guidelines for storytelling:

- Think about illustrative stories ahead of time when you are planning your training. You do not necessarily need to write a story out word for word, but make notes so you remember key points of the story.
- Change names and perhaps a key detail in order to respect confidentiality.
- Be sure there is a practical application.
- Keep it short and to the point, but put in enough details to make it interesting.
- Practice storytelling! Some of us are natural storytellers, and some of us are not. You will get better at it, the more you do it.
- Use it to drive home a point.

Storytelling Example: Fishing

by Jim Wealton

“John has lived in a medical care facility for more than a year. He has no close relatives to visit and never married, having worked and lived in the woods of Northern Michigan. He has been a rather cantankerous person for several years and is not always pleasant to those who attempt to converse with him. He spends most of his days in his room watching television or simply looking out his window.

While visiting one day, I noticed he had only one picture hanging on his wall over his bed. To engage him in conversation, I took the picture off the wall with his permission and asked who the people were.

John was in the center surrounded by three other friends whom he immediately was able to identify. There was also a pretty nice catch of lake trout they had caught on an outing earlier that day. He proceeded to describe his fishing trip with his friends (who have not visited him) and the fact that they had caught their limit of trout. He then became very quiet and leaned over and whispered in my ear, "We caught one more than the limit but please don't tell anyone."

John then asked if I would like to see his fishing poles. I agreed, thinking that he probably didn't have them in the nursing home. He went to his closet and produced two reels and fishing rods. He then pulled a rather large tackle box out of his closet and began to describe a host of lures to me and what type of fish could be caught with each lure. This went on for several minutes until I had to leave.

For a little while, John had had an opportunity to reminisce about a time in his life that was important. A time when his friends and activities had a focal point, a time when things were better and happier. His opportunity to go back in time started with looking at a simple picture on his wall. Each time I visit John, I take the picture off the wall and he tells me the same story. For me, it's like seeing the same movie over and over. For John, it's like telling the story for the very first time. And isn't that what it's all about?"

Adding Humor to Your Training

by Barbara J. Kendall

Why should you consider adding humor to your presentations? Why take the time to look on the lighter side of your curriculum? The answer is clear – with the addition of humor to your training, it will have a greater chance of success. A humorous story, cartoon, quote, or picture can help you set the tone for an enjoyable training experience. Participants can be introduced

to a learning environment that is accepting as they share the experience of smiling or laughing with their instructor and fellow learners.

Staff who give care to individuals with Alzheimer's disease or other dementias often face very difficult issues associated with caregiving.

- Humor can become a method of shortening the distance between the instructor and staff.
- Humor can acknowledge everyone's humanity and allow people to look at the experience as one to be shared.
- Humor can also reinforce important training points and strategies of care, which may then be remembered more easily by staff.
- Humor can be modeled by trainers, so that staff incorporate it into their work with residents.

How can a trainer add humor to a presentation? Training content in this field is often very serious, far from the lighter side of life. And you, the trainer, may not consider yourself a humorous person. Yet, humor can still become a component of your training. Consider the following suggestions as places to start:

- **Think humor.** Look for amusing stories, cartoons, pictures, or any thing that you find funny. Keep these ideas in a humor file, or put them in a spot that will bring a smile to your face during the day. In this way you will be more attuned to the idea that humor is an important part of your work. Your humor file will also give you direction as you plan your training. Then add those pieces of humor to your presentation to make a point, make a space between thoughts, or just put a smile on the face of your audience.
- **Teach staff to look for the lighter side of their work.** Staff may have humorous stories of caregiving, but

because the situation was so painful or distressing, they may not feel comfortable sharing them. Give staff permission to laugh at themselves and the situation without personal embarrassment or dishonoring the resident. Sharing an amusing caregiving situation can be an important survival skill. When staff share similar situations, training can become a bonding experience.

- **Train with a smile and share feelings of well being.** Training needs to take place in an atmosphere of comfort and sharing. Anxiety and stress are contagious emotions. We need to model an instruction style where participants feel valued for sharing with the group. You can put participants at ease with a smile and by demonstrating interest in staff experiences. Bill Cosby is credited with saying, “If you can find humor in something, then you can survive it.” Is this not good advice for all of us – trainers and trainees alike?
- **It is important both for ourselves and our staff to be sure that our humor does not dishonor or make fun of residents, and does not attack others’ values or self-esteem.** Humor is sometimes a matter of taste – look for funny events and cartoons, but be sure they are in good taste.



SLIPSHEET

Session 1: Introducing Alzheimer's Disease and Related Dementias

Anne Robinson, Beth Spencer, and Chris Curtin
With Disease Summary Sheets by Shelly E.
Weaverdyck

Interactive Training Strategies

- True / False Quiz. This is a short quiz about dementia, which might be used to begin a training session. We have redrafted the answers to the questions for trainers. This can also be used as a Staff Handout.
- Discussion questions. These provide a framework for brainstorming key points in an overview of dementia.
- Video clips of Edna Gates at four points in the course of Alzheimer's disease. These are accompanied by background information, an introduction and discussion questions at each stage.
- Powerpoints that follow the *Outline for Trainers*.

SUGGESTIONS FOR CONDUCTING SESSION 1:

Introducing Alzheimer's Disease and Related Dementias

The goals of this session are:

- To help staff understand that the behaviors and symptoms of dementia are not intentional and are the result of a brain disease, not of normal aging.
- To teach staff what dementia is, about the diagnostic process, and to make them aware of the variety of causes of dementia.
- To teach staff about the common symptoms and behaviors associated with progressive dementia, including Alzheimer's disease, Dementia with Lewy Bodies disease, Multi-Infarct or Vascular dementia, and Parkinson's disease.
- To help staff begin to see residents as individuals with a history.

Using the *Outline for Trainers*

The *Outline* outlines key information that should be part of an overview of dementia; it may have more detail than you think your staff need. You can tailor it to your needs or can spread the information over several sessions. In addition to the basic information laid out in the *Outline* and the transparencies, we have suggested a number of ways to make this information interactive and of interest to staff.

The key is to get staff interested in the topic and involved immediately.

As discussed in *Training Staff: Issues to Consider*, using different training techniques and formats is very helpful. Listed below are several ways we have found of presenting this information:

- Begin with discussion questions instead of a lecture.
- Begin with the True / False Quiz.
- Use the video clips of Edna Gates (or other videos if available) to illustrate one person's progression through Alzheimer's disease.

Discussion Questions

It can help to involve staff in brainstorming early on. You can use the powerpoints on the disk as backups or summaries of the brainstorming. After a short introduction and some definitions, we often brainstorm, using some of these discussion questions:

- What do you think normally happens to our memories and thinking abilities as we grow older?
- What things affect how well our memory works?
- What are some of the symptoms or behaviors you associate with Alzheimer's disease or other dementias?

(Make lists of their answers. As you work through the outline, come back to the list and clarify, make comments or corrections to the list staff came up with.)

True / False Quiz

Another way to begin an Overview of Dementia is to use the True / False Quiz. Make it a fun activity, not a test. The Quiz we have included was developed by Tom Kitwood, a British dementia expert. We have rewritten the answers to reflect American terminology and statistics.

Ask the staff whether they think each statement is true or false. You can either have them write it down or raise their hands. But make sure they are clear that this is not a test – it is simply a way to see what they already know, and which areas you should concentrate on.

Use the answers to discuss the various points as an overview and as a handout .

Videotapes

Using videos that show people with dementia at different points in the illness is one way of making the issues real to staff. One way to help staff think about some of the changes that occur with the progression of dementia is to use a series of videotape vignettes illustrating one person's experience with dementia over time. Below is information about using the Training Tape, followed by suggestions of other videos.

Edna Gates Training Tapes

There are four videotape vignettes that focus on one individual living with dementia, Mrs. Edna Gates. In the first vignette Mrs. Gates is moderately impaired; the last vignette shows her with advanced stage dementia. The following background information was compiled by her family. **Trainer:** It would be useful to read this to staff before they watch the video clips.

Mrs. Gates (1913-1995) grew up in central New York, finishing high school at the age of 15. She was a middle child in a family of six children. She moved to Syracuse as a young child and grew up in a home on the edge of the woods. As a teenager, swimming, ice skating and horseback riding were favorite sports. Mrs. Gates attended Cornell University on a full scholarship and then embarked on a 30 year career as a civilian employee of the federal government. As a secretary, Mrs. Gates worked with Senator Robert LaFollette Jr. while he investigated the condition of migrant workers during the Dust Bowl Era. In the last months of World War II, she went to London as an employee of the OSS, precursor to the CIA. In post-war Berlin, she worked with U.S. Army General Lucius Clay while he governed the city during the Russian blockade. Mrs. Gates was a competent, independent and forward thinking woman who had a challenging professional career at a time in history when there weren't many women working.

Mrs. Gates married in her mid-forties. She traveled the world with her husband, spending time in Japan, Africa, Europe and England, and talked passionately about her interactions with people from different cultures.

She began to develop symptoms of dementia in her early 70's and was diagnosed with probable Alzheimer's disease in 1974. Her husband cared for her and used adult day care services to provide much needed respite. Mr. Gates died suddenly of a heart attack leaving Mrs. Gates on her own. Her older sister from Ann Arbor, Michigan, made arrangements to bring Mrs. Gates to Huron Woods, where she lived for approximately four years before her death.

Mrs. Gates was a strong, physically fit woman who loved to go for walks. She enjoyed the serenity and beauty of the outdoors. Mrs. Gates often reminisced about playing basketball in her younger years and enjoyed telling stories about being on a varsity team at Cornell University. She had a wonderful sense of rhythm, loved to dance and enjoyed listening to a variety of music including classical, musicals and opera. Mrs. Gates appreciated the cultural arts; her bedroom at Huron Woods was filled with an unusual collection of Impressionist paintings and antique furniture. She was a private woman who would often retreat to her room for time alone.

Mrs. Gates had a keen sense of right and wrong and reacted strongly when staff were condescending towards her. During these moments, she would become verbally upset and frustrated. Mrs. Gates was profoundly aware of the changes that were occurring in her abilities and was devastated by these changes.

Videotape Vignette #1 of Edna Gates, January 5, 1994

At Huron Woods, Mrs. Gates was a member of a reminiscence group, which met once a

week for an hour. The purpose of this group was to provide opportunities for five women with similar abilities to reminisce about their pasts and to reflect on the joys and disappointments in their lives. The group was carefully structured to enable the group members to successfully participate. There was a specific seating plan, introductions, refreshments and a closing ritual. A sense of trust, intimacy and friendship developed among the women as they began to come out of their shells to share their feelings and stories. Two of the Huron Woods staff co-facilitated the group.

In the first vignette, you will see Mrs. Gates (wearing a red dress) reminiscing about her life. Through a process of trial and error, the facilitators had learned what questions were most helpful in triggering memories about her life. As you and the staff watch the video, keep in mind the following questions:

- What are Mrs. Gates' remaining abilities and strengths? For example, her lovely sense of humor, her social skills, ability to recall things about her past.
- What are some of the challenges Mrs. Gates is experiencing because of some of the brain changes? She is having difficulty saying certain words – uses the word “cookie” to describe different situations.
- Describe Mrs. Gates' mood during the small group experience. She appears relaxed, animated, enjoying the friendship of others in the group.

Videotape Vignette #2, June 6, 1994

Mrs. Gates had been invited to join a small dinner group, which met once a week. The purpose of this group was to provide a pleasant mealtime experience for four women with moderate dementia. The group was carefully structured and members were encouraged to eat independently and to socialize with each other between courses.

In the vignette, you will notice Mrs. Gates (in the light green outfit) at the top of

the screen. She has just been invited by one of the staff to join the dinner group. Unfortunately, the staff did not consider the order in which group members were invited to the dining room. Mrs. Gates did best when she was the last person to be invited to the group. Because of the brain damage to her frontal lobe, she had difficulty adjusting to new situations and to the commotion involved as people entered the dining room and were seated. You will see Mrs. Gates become increasingly frustrated. As you and the staff watch the vignette, keep in mind the following questions:

- What are Mrs. Gates' remaining abilities and strengths?
- What are some of the difficulties Mrs. Gates is encountering during the first few minutes of the dinner group?
- Describe Mrs. Gates' overall mood. How can you tell she is frustrated and upset?
- What other approaches could the staff have used to help Mrs. Gates relax and focus on the activity of eating?

Videotape Vignette #3, June 1, 1995

Here you will see Mrs. Gates having lunch in a small room with a staff member. She has declined considerably and is no longer able to cope with the noise and confusion in the main dining room with lots of people eating together. The commotion caused her a great deal of distress – she would get up and down from the table and become angry with others in the room. She was also having a great deal of difficulty staying focused on the task of eating. Hence, staff decided to explore ways to create a calm and relaxed environment with minimal stimulation at mealtime. Staff were focused on looking at ways to help Mrs. Gates eat independently using finger foods. As you and the staff watch this vignette, keep in mind the following questions:

- What are Mrs. Gates' remaining abilities and strengths?
- Describe some of the difficulties Mrs. Gates is having because of the brain

changes related to dementia. For example, her inability to stay focused on the task of eating. Mrs. Gates is no longer able to follow or “model” the staff member when she is eating her sandwich.

- Describe Mrs. Gates’ mood.
- Critique the staff member’s style of communicating with Mrs. Gates. What is she doing that is helpful (or not helpful)?

Video Vignette #4, August 31, 1995

Mrs. Gates is significantly more impaired and needs a great deal of assistance from the staff. Not long before, she was diagnosed with secondary cancer. In this clip, the staff member is focused on creating a pleasant atmosphere and looking at ways to encourage Mrs. Gates to eat soft foods and liquids. As you and the staff watch this vignette, keep in mind the following questions:

- What are Mrs. Gates’ remaining abilities and strengths?
- Describe Mrs. Gates’ mood.
- What are some of the approaches the staff member uses to encourage Mrs. Gates to eat?

Some wrap-up comments for you as the trainer to consider:

- Brain diseases, such as Alzheimer’s disease or strokes, affect different functions or centers in the brain. They are progressive. There is much, however, we can do to help people with dementia lead a quality life.
- As caregivers we can:
 - Take the time to get to know the people we serve as individuals who have a unique life story;
 - Consider their feelings;
 - Take the time to talk with people – every moment of contact we have with a person with dementia is significant – every task we do is an opportunity to make a meaningful connection;

- Respect them as equals;
- Help people with dementia to use their remaining abilities;
- Be there to support them in whatever way they may need help.

Other Videotapes

There are a number of commercial videos that tell one person’s story, or show different people at different stages. Several examples are below. It is important to emphasize that a video only shows one person’s experience with the disease – **every individual with a dementia has a different experience.**

We have found that the most effective way to use these is to show 5-10 minutes segments and then stop and discuss what we’ve seen.

Staff often find it helpful to talk about the progression of symptoms in Alzheimer’s disease. We have included a handout that describes symptoms at early, middle, late, and end stages. Several points are important to make about this:

A note about stages: There is controversy about whether to teach stages of Alzheimer’s disease. We have chosen to discuss the progression in terms of early, middle, late, and end stage symptoms. These are general and **it is important to make the point that individuals do not always fall easily into one stage, that the illness progresses differently in different people.** It may be helpful to point out to staff that there are complex stage theories, such as Barry Reisberg’s Global Deterioration Scale (1983), but there are also experts such as Virginia Bell and David Troxel who do not believe in staging at all, as they think it depersonalizes (1997, p. 31).

Complaints of a Dutiful Daughter. A daughter tells the story of her mother’s illness retrospectively. We see shots of her at home and after move to nursing home. This video looks at different stages and behaviors, and does so with a sense of humor. (*Length: 45 minutes. There are clear segments where the video could be stopped and started.*)

- What changes do you see in the mother over time?
- When the mother is still living on her own, what abilities and strengths do you see?
- At the point where she moves into the nursing home, what strengths do you still see in the mother?

Grace. A husband tells the story of his wife over a 7 year period. We see her at 3 very different points in the illness. There are many possible vignettes to use to illustrate strengths and difficulties. (*Length: 50 minutes. 3 distinct segments. Could use only part of each segment.*)

- What are some of the symptoms of Grace's dementia?
- What feelings or emotions does Grace show?
- What changes did you see from the earlier segment?
- What abilities does Grace still have? Strengths?

From Here to Hope: The Stages of AD: final, middle and early. This video highlights different individuals at different points in the illness. The late stage individual is the author of *Partial View: An Alzheimer's Journal*; we see brief clips of him at earlier points (16 minutes). One of the middle stage individuals is a musician, still living alone and attending day care (21 minutes). One of the early stage individuals is modeling for her daughter's photography project (17 minutes). (*Total length: 77 minutes.*)

- What strengths and abilities do you see at this point in the person's illness?
- What tasks/things is this person still able to do?
- What does the individual say about how he or she wishes to live?

Materials on the CD for this session:

Staff Handout: Progression of Alzheimer's Disease

Staff Handout: True / False Quiz

True / False Quiz Answers

Sources of Information on Dementias

There are a number of organizations that provide information and support to people with AD and a related dementia, including:

National Alzheimer's Association
225 North Michigan Ave., Fl. 17
Chicago, Illinois 60601-7633
800/272-3900 to locate the chapter nearest you and ask for their educational materials
Web site: <http://www.alz.org>
24/7 Helpline 800/272-3900

Alzheimer's Disease Education and Referral (ADEAR) Center
PO Box 8250
Silver Springs, Maryland 20907-8250
800/438-4380
E-mail: adear@alzheimers.org
Web address: <http://www.alzheimers.org>

Huntington's Disease Society of America
505 Eighth Ave. Suite 902
New York, NY 10018
800/345-HDSA
<http://www.hdsa.org/site/PageServer?pagename=homepage>
General Inquiries: hdsainfo@hdsa.org

American Parkinson's Disease Association
135 Parkinson Avenue
Staten Island, NY 10305
Phone: 1-800-223-2732 or (718) 981-8001
Fax: 1-718-981-4399
E-Mail: apda@apdaparkinson.org
<http://www.apdaparkinson.org/user/index.asp>

National Organization for Rare Disorders
PO Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673
<http://www.rarediseases.org/>

SESSION 1

OUTLINE FOR TRAINER

Introducing Alzheimer's Disease and Related Dementias

Introductory Comments

What is normal forgetfulness?

What is not?

Aging is a process of change. As we grow older our bodies change in a variety of ways. Our senses, particularly **vision and hearing**, change – our eyes, for example, may have difficulty distinguishing pastel colors. We may need more light to read or work on tasks. Our ears lose their sensitivity to certain frequencies. **Physical functions start to slow down.** These changes are a normal part of aging.

Trainer: Use discussion questions or True/False Quiz here.

What do you think happens to our memory and thinking ability as we grow older?

- **We take longer to learn new information or skills.** The saying “An old dog can’t learn new tricks” is not true. It just takes an older dog longer!
- **It is harder to retrieve information from our long term memories** because there is so much information that has been filed away.
- **We need more memory cues for recall.** Our memories have a harder time retrieving information as we get older, so it may take more cues for us to remember.
- **We take longer to remember certain types of information** like names or places.
- **We’re more easily distracted**, which can affect a person’s memory.
Background noise or lots to look at can

easily cause us to have trouble with our memories.

- **Our memories are more affected by fatigue, illness, stress, grief, certain medications, vision and hearing loss or by a lack of concentration.** Such losses can occur at any age and can be reversed when the stress lets up.

These minor memory lapses are often referred to as “**benign forgetfulness.**” While the memory loss is annoying, it does not significantly disrupt the person’s life.

Most people with **normal memory loss can compensate** by writing reminders to themselves, making lists, allowing time for remembering or repeating out loud the information they want to remember.

There are a growing number of older adults who experience **persistent forgetfulness but have no other difficulties with thinking.** This condition is referred to as “**mild cognitive impairment.**” There is growing evidence to suggest that changes in the brain are occurring and that these changes are the same processes that cause AD.

When memory problems become severe enough that they interfere with normal daily living activities, this is not normal aging. Most likely it is the result of a disease. Problems with concentrating, following directions, handling finances and keeping track of conversations are symptoms that indicate something far more serious is going on.

What is dementia? What is delirium?

Dementia comes from Latin meaning “**from the mind**” or “**out of mind.**” It has been mentioned in the Bible and in early Greek and Roman writing suggesting that it has affected people for many, many years.

To many, the word dementia implies craziness and hopelessness – this is not true.

Dementia is a term used to describe a group or pattern of symptoms characterized by a decline in intellectual abilities from a person's previous state.

- Noticeable **change in the person's thinking abilities** from the way he/she used to be.
- Not caused by a single disease, but rather **many different diseases or problems can cause dementia**.
- **Person is alert and awake**. This element distinguishes dementia from delirium.
- **The preferred term now**, instead of senility, organic brain syndrome, hardening of the arteries.
- **Not the name of a single disease**.
- **Caused by many different conditions**, some treatable, some not.

Delirium is a condition in which there is an **acute, reversible change** in a person's behavior – acute meaning that it happens **suddenly**, reversible that it can often be **treated and reversed**.

- Characterized by a **clouding of consciousness**, the person is inattentive or unable to sustain concentration.
- **Frequently caused by medication toxicity, abnormal electrolytes or an infection** such as a UTI or pneumonia.
- Delirium is **often reversible**. It is important that staff watch for **sudden changes** in sleep patterns, increased agitation or irritability, fever, pain, restlessness or recent incidents of urinary accidents.

Symptoms of Dementia

Memory loss and impairment in one or more of the following:

- **Language abilities** – person may have trouble understanding spoken word and written communication, may have difficulty finding words.
- **Disorientation to time or place** – need

to be reminded of what day it is or to be given directions to places that were once familiar.

- **Ability to do calculations** such as balancing check book.
- **Difficulty performing familiar tasks** – forgetting recipes in cooking, neglecting household chores, trouble with shopping.
- **Poor or decreased judgment** especially with driving and operating other appliances.
- **Changes in behavior or personality** – person may begin to withdraw socially, may have explosive angry spells, may become disinterested, easily frustrated.

Causes of Dementia

Dementia is caused by a **disease of the brain**.

- A process that causes something to be broken in the structure or function of the brain.
- More than 80 different medical conditions that can cause dementia, including:

Degenerative Brain Diseases

Alzheimer's disease (AD)

Dementia with Lewy Bodies (or Lewy Body Dementia)

Parkinson's disease

Huntington's disease

Progressive supranuclear palsy

Multiple sclerosis

Frontotemporal degeneration (or Frontal Lobe dementia)

Pick's disease (a form of Frontal Lobe dementia)

Cerebrovascular Diseases

Multi infarct disease (stroke)

Infectious Diseases

Syphilis

HIV (AIDS dementia complex)

Creutzfeld-Jakob disease (related to "mad cow disease")

Vitamin Deficiencies

Vitamin B12 deficiency

Vitamin B6 deficiency

Vitamin B1 (Thiamine) deficiency

Toxin Exposure

Alcohol

Medications

Heavy metals (lead, mercury, arsenic)

Endocrine Diseases

Diseases that affect the thyroid

Brain Tumors

- Estimated that **50-65%** of dementia is caused by **Alzheimer's disease**.
- **Controversy about second most common cause** of dementia – vascular dementia (multi-infarct) or Diffuse Lewy Body dementia.

The Importance of a Comprehensive Dementia Evaluation

- Recognizing symptoms and obtaining an **accurate diagnosis is very important**.
- **Dementia is sometimes caused by treatable conditions**, such as medication side effects, nutritional deficiencies, or depression.
- **Early, accurate diagnosis is important in determining the course of treatment** and managing symptoms such as depression or agitation.
- **It enables the person and his/her family to plan for the future** while the person with memory loss can still take part in making decisions.
- There are **medications such as Aricept and Exelon** which are available for individuals diagnosed with mild to moderate Alzheimer's disease. **These medications do not reverse the progression of AD**, rather they are intended to enhance memory

functioning. Many others are currently under investigation.

- The medical specialists who are most attuned to diagnosing dementia are **neurologists, psychiatrists, and geriatricians**. Most large cities have specialized diagnostic or geriatric assessment clinics.

Key Components of a Dementia Evaluation

- **Medical and family history** – observations about when symptoms first began, personal and social history, substance abuse, history of present illnesses, current living situation.
- **Physical exam** – look for presence of cardiac, respiratory, liver, kidney, thyroid disease – also evaluate the person's nutritional status, blood pressure, pulse.
- **Laboratory tests** – EEG, blood tests, urinalysis.
- **Cognitive screening** – e.g., Mini-Mental Status Exam (MMSE), to assess the person's sense of time and place, comprehension, memory, ability to do simple calculations, ability to complete mental exercises.
- **Neurological exam** – look for evidence of previous strokes, brain tumors, other disorders known to affect memory and thinking.
- **Brain imaging** such as a CT scan (computerized tomography). This procedure examines brain tissue via X-rays. It is used to detect the presence of tumors, strokes, blood clots. Sometimes a **PET** (positron emission tomography) scan is done; this procedure is used to try and detect changes in the way glucose is metabolized in parts of the brain that are most affected by AD. The **MRI** (magnetic resonance imaging) is used to measure the size of various structures in the brain.

- **Psychiatric exam** – to rule out the presence of depression or other mental illness.
- **Neuropsychological testing** – paper and pencil tests designed to assess cognitive skills involved in different functions of the brain. This information can be particularly helpful when planning interventions.

Not everyone necessarily has all of these tests (depends on age, health, history, resources, insurance, etc.)

Once all the tests are done, the results are evaluated and a diagnosis is given.

- **Clinical criteria have been established to help guide physicians** in making a “probable” or “possible” diagnosis of AD or another dementia.
- **Accuracy rate by experienced physicians is 85%** or greater as confirmed by autopsy.
- **Some individuals have not had a thorough evaluation** and do not have an accurate diagnosis.
- **Families handle diagnoses in different ways.** Some individuals may have been told by their families or doctors that they have AD (or whatever their diagnosis is). Others may not have been informed. **It is important for staff to be informed and sensitive to the terms used by the family and physician** to describe the memory loss.

Facts about Alzheimer’s Disease

Alzheimer’s Disease Facts and Figures, 2007

- **AD has been around for a long time.** In 1906, Dr. Alois Alzheimer described a 51 year woman whose memory and personality deteriorated gradually while she developed problems understanding, speaking and writing. After the woman’s death, Alzheimer examined her brain and found the characteristic plaques and tangles.

- It is estimated that over **5.1 million people in the U.S.** have AD.

“I have recently been told that I am one of the millions of Americans afflicted with Alzheimer’s disease.”

Ronald Reagan, November 4, 1994

- **More women than men have AD.** This is partly because women tend to live longer and there are more older women.
- **More than 70% of nursing home residents have progressive dementia,** mostly AD.
- **AD can only be diagnosed with 100% certainty by a brain autopsy** (i.e. examination of brain tissue under a microscope) after death. A small piece of brain tissue is removed surgically and a pathologist looks for the tiny brain lesions (plaques and tangles). **But accuracy rate by experienced physicians is 85%** or greater. The majority of people do not have brain autopsies, which have to be arranged ahead of time.
- **Average length of disease is 7-10 years** after the person has been diagnosed, but it varies from 3-4 years to more than 20 years.
- **Average cost of caring** for a person with AD varies from \$18,408 /year for a person with mild AD, to \$36,132 /year for late stage AD. (Leon et al., 1998, cited in NIA Progress Report, 1999).
- **70% of people with AD live at home.** Three out of every four caregivers are women.
- **The cause(s) of AD are still not fully understood,** although great progress in brain research has been made in the last 20 years. Many researchers believe that **multiple factors are involved** in the development of AD, factors that may interact differently in different individuals.
- **Death is usually from a secondary problem** such as pneumonia, a urinary tract infection, or not being able to

swallow, which leads to not eating. The massive loss of nerve cells eventually affects the auto immune system and the body is not able to fight off infections.

Risk Factors for AD – The factors that researchers have identified that indicate that a person is at greater risk of developing AD. **Increased risk does NOT mean the person will necessarily get it** (compare to risk factors for heart disease or cancer).

- **Advanced age.** There is an increased chance of getting AD as we grow older. The risk of getting AD doubles about every five years after age 65. People less than 65 years of age represent a very small minority of the total number of people with AD.
- **Family history of AD.** It is well established that those who have a first degree blood relative (parent, sibling) has been diagnosed with AD are 1-2 times as likely to develop AD as those without a family history of the disease. Although risk is increased by a family history of AD, **there is still no certainty of getting the disease.**
- **Genetics.** In a very small number of cases, there is a definite genetic link in families whose members get the disease in middle age. This rare form of the disease is referred to as Familial AD. This form of the disease has been traced to mutations on chromosomes 1, 14, and 21.
- **Down's syndrome.** Another genetic risk factor concerns people with Down's syndrome, a form of mental retardation linked to chromosome 21. When their brain are examined under a microscope during autopsy, middle-aged people with Down's syndrome have similar changes in brain tissue consistent with AD.
- **History of head trauma.** Several studies have shown that suffering a severe blow to the head resulting in loss of

consciousness increases the risk of developing AD later in life. It is well known that professional boxers who suffer repeated blows to the head are at high risk of impairment to their memory and other brain functions.

The Progression of Alzheimer's Disease

Trainer: Use Edna Gates vignettes from Training Tape or other videotape clips here. Refer to the discussion questions and background in *Suggestions* section.

- **Onset of symptoms is gradual and progressive.** Changes are subtle and it may take several years before person is evaluated.
- **Every individual has his/her own experience.** We are seeing one person's experience in these videotapes. While it is helpful to view this, it is important to remember that each person with Alzheimer's disease has a different journey.
- **The rate of progression from the milder to more severe stages is gradual and differs from individual to individual.**
- **People who have a relatively early disease onset (in their 50s) often deteriorate more rapidly than those whose onset is later in life.**

Early Stage

- **Hallmark of AD is loss of recent memory.**
- **Loss of word-finding ability** is commonly the first language difficulty.
- **Increasing difficulty paying attention, reasoning, and understanding abstract concepts,** such as balancing a check book or estimating how much a cartload of groceries cost.
- **May develop difficulties with driving.**
- **Inability to adapt to change** or new situations at work.
- **Subtle changes in personality** – may show indifference, lack of initiative.

- **Social skills generally well preserved** – often skillful in hiding any problems with memory and thinking.
- For the most part, **person can complete basic self-care tasks.**
- To a casual observer, the **person looks physically normal.**

Middle Stage

- **Comprehension of written and spoken language deteriorates** especially when complex topics are involved.
- **Changes in speech** – still generally use correct grammar. Speech often remains fluent – person may begin to say meaningless statements with made-up or sound-alike words.
- May begin to be **repetitive** in conversations, phrases, or questions.
- More easily distracted and may often digress, spending more time on talking about topics from the past.
- More likely to withdraw in difficult social situations where there are many people involved in a discussion.
- Certain behaviors may become increasingly problematic – day/night cycle is confused, agitation, wandering. May show signs of frustration with their inability to communicate, becoming angry or argumentative.

Late Stage

- **Memory of recent events is seriously compromised.**
- **Long term memory significantly more impaired.**
- **Severe communication difficulties.** Some comprehension may still be there – can still understand emotion and tone of voice of the staff person.
- **Difficult behaviors become less of a focus.**
- **Emphasis is on providing a great deal of assistance with ADLs.** Person is dependent on staff for personal care.

- **Incontinence creates challenges** with bathing and toileting.
- **Decreased appetite** – person may lose weight.
- **May not recognize self or family.**
- **May still be able to ambulate** with encouragement and assistance by staff.

End Stage and Dying

- **Physical care very demanding** for staff.
- **Pain assessment and management** an ongoing challenge.
- **Eating and hydration** become difficult.
- **Immune system compromised.** More vulnerable to urinary tract infections, pneumonia, and sepsis.
- **May no longer be able to ambulate safely.**
- **Skin breakdown** may occur.
- While the person with AD may be withdrawing, **with carefully structured experiences, there may be ‘momentary awakenings’** where the person is responsive to music therapy, sensory stimulation, massage etc.

Trainer: See Alzheimer’s Disease: A Summary Sheet at the end of the Outline.

Multi-infarct Dementia (MID) ***Sometimes referred to as Vascular Dementia***

- A form of **progressive dementia.**
- **Caused by small strokes** that occur in the brain. Stroke occurs when a blood clot gets lodged in an artery in the brain, blocking the flow of blood past the clot, or where the arteries in the brain harden (atherosclerosis) to the extent that blood cannot flow through. If the blockage does not let up, the nerve cells in the area of the brain not receiving blood will die. The area of tissue that dies is called an infarct.
- **Symptoms similar to those of AD,** including memory loss, difficulty communicating, and

often hallucinations, delusions, and depression. However, there are some distinctions that set MID apart from AD.

- **Abrupt onset of dementia** symptoms that often progress in “steps” with abilities remaining steady for a period of time, then declining rapidly. This **step-wise decline** in function is due to the random occurrence of strokes in the brain.
- Usually affects people **between the ages of 60 and 75**.
- Usually linked to **risk factors for stroke**, such as high blood pressure, heart disease, or diabetes.
- **Treatment of risk factors**, particularly hypertension, can slow further deterioration in abilities.

Related Dementias

A number of degenerative conditions other than AD that have been identified by researchers in the last decade. While these conditions may look like AD, they aren't. They are called **Alzheimer's mimics**. It is likely that there are other conditions that have not yet been described or named.

Features of dementias that are not AD:

- age of onset before age 60
- sudden onset or rapid progression
- early behavior changes or hallucinations
- early incontinence or seizures

Even when individuals meet all the criteria for a diagnosis of probable AD, 10-15% will have an alternative diagnosis discovered at autopsy.

Trainer: See Summary Sheets on Dementia with Lewy Bodies (DLB) and Frontotemporal Dementia (FTD) at the end of this *Outline*.

- **May be the cause of up to 20% of dementia cases**; some researchers are saying that DLB may now be

the second most common cause of dementia in the U.S.

- **Often seen in combination with AD.**
- **An irreversible form of dementia** that is associated with abnormal protein deposits in the brain called Lewy bodies.
- **Symptoms similar to AD.** Include memory loss, confusion, and difficulty communicating thoughts and following conversations.
- **DLB characterized by three features:**
 - **Fluctuations in cognitive abilities.** For several days or weeks, person may function quite well. Then there may be a series of “bad days” in which the person's cognitive abilities (particularly attention and visuospatial skills) will suddenly decline. Difficult sometimes to distinguish this from a delirium.
 - **Visual hallucinations.** May see things or people that are not really there, especially during the early stages.
 - **Movement problems.** Difficulty with balance, stiffness, slowed movements, stooped posture and sometimes a gait shuffle.
- **Person with DLB is very sensitive to traditional antipsychotic medications** which are used to control behavioral symptoms.
- **Distinction between AD and DLB is important** because it affects treatment and care a person receives. Staff need to be aware that the person's cognitive and functional abilities may suddenly decline and that the person may need extra attention or help with tasks during this time.

Parkinson's Disease (PD)

- **Most common over the age of 60**, but about 1/3 under age 50.
- Estimated that about 1 million people in U.S. have PD.

- Sometimes individuals in the later stages of PD develop dementia, (20-30%) and symptoms of memory loss and cognitive impairment become noticeable. But not everyone who gets PD develops dementia.
- Caused by the loss of brain cells that produce dopamine, a chemical that controls muscle activity in the nervous system. Medications are designed to “replenish” the dopamine supply in the brain to help nerve cells communicate more effectively. These medications help alleviate most symptoms associated with the disease, but will not stop the progressive deterioration.
- Primary symptoms include:
 - Tremors or shaky movements of the hands, arms, legs and face.
 - Rigidity or stiffness of the limbs and trunk. So-called “Parkinson’s mask” is the lack of facial expression which sometimes occurs in individuals due to rigidity of facial muscles.
 - Poor balance and coordination. Falling backwards is a common problem in PD.
 - Decreased movement, slowness. Early symptom is often that person no longer swings arms when walking.
- A chronic and progressive disease.
- PD is not inherited, though increased risk if parent or sibling had it.

Huntington’s Disease

- A rare, hereditary disease. The genetic defect is found on Chromosome 4. Children of affected individuals have a 50 percent chance of inheriting this gene.
- Onset of symptoms usually between the ages of 35 and 40.
- Characterized by involuntary muscle movements, generally limbs and/or facial muscles.

- Other symptoms include delusions, hallucinations, paranoia, and depression.
- Drastic changes in mood are also common.
- Pattern of memory impairment quite different from that in AD. As the condition progresses, movements become severe and uncontrollable and memory loss and decline in a person’s cognitive abilities also occur.
- Medications can treat the movement disorders and psychiatric symptoms; however, there is no treatment available to stop the progression of HD.
- Genetic testing and counseling available for HD.

Pick’s Disease (a form of Frontal Lobe Dementia)

- A relatively rare form of dementia.
- Average age of onset between 50-60 years.
- Memory loss NOT the most noticeable sign of early Pick’s disease. Instead, the first signs include distinct personality changes. Strange behavior may include increased irritability and aggression, poor judgment, increased eating and weight gain, and inappropriate sexual behavior.
- Severe memory loss not typical until the final stage of the condition.
- Memory impairment usually involves an inability to find appropriate words or understand everyday conversation.

Concluding Remarks

- Probably many other forms of dementia yet to be discovered.
- Brain autopsies an important way to determine the true cause of dementia.
- Useful to know something of the different forms of dementia. **But most important thing is to treat all residents with respect and dignity.**

- Brain diseases, such as Alzheimer's disease or strokes, affect different functions or centers in the brain. They are progressive. There is much, however, we can do to help people with dementia lead a quality life.
- As caregivers we can:
 - **Take the time to get to know the people we serve** as individuals who have a unique life story.
 - **Consider their feelings.**
 - **Take the time to talk with people.** Every moment of contact we have with a person with dementia is significant. Every task we do is an opportunity to make a meaningful connection.
 - **Respect them as equals.**
 - **Help people with dementia to use their remaining abilities.**
 - **Be there to support them in whatever way they may need help.**



ALZHEIMER'S DISEASE (AD)

A Summary Sheet of Information and Intervention Suggestions With an Emphasis on Cognition

By Shelly E. Weaverdyck, PhD

CHARACTERISTICS

Brain disorder

Most obvious symptoms: memory loss and cognitive impairment

Progression: increasing severity of symptoms over time (a progressive dementia)

Onset: insidious; age 40-90, usually over age 65 (median age 73.5)

Duration: average 8 years from onset to death (may vary with time of diagnosis)

Cause unknown

Cure: no cure at this time, but there is treatment to reduce symptoms

Diagnosis verified at autopsy

Is the most common cause of dementia (60% of all dementia cases)

Affects 10% of all people over age 65

Risk factors: age, APOe4 gene, Down's Syndrome, family history

Hereditary in 10% of cases

Course: gradual, steady decline, decline 2-4 points per year on Folstein Mini-Mental State Exam, no spontaneous improvement

Alois Alzheimer first described neuropathology in a 51-year-old woman in 1907

NEUROPATHOLOGY

Neuritic plaques outside of cells in brain

Neurofibrillary tangles inside of cells in brain

Atrophy (i.e., loss) of brain tissue; cell death

Acetylcholine reduction

LOCATION OF CORTICAL BRAIN CHANGES

Cortical refers to the cortex (i.e., the outer layer) of the brain

Changes (pathological abnormalities) occur in the cortex and in internal (subcortical) structures of the brain

Changes (pathological abnormalities) occur on both sides of the brain

Order of cortical brain structures affected, creating stages:

Hippocampus (subcortical)

Parietal lobes

Temporal lobes (posterior then anterior)

Frontal lobe

COGNITIVE CHANGES

Memory impairment first obvious symptom

Visuospatial perception and skill impairment:

Difficulty recognizing distance between objects and from self

ALZHEIMER'S DISEASE (AD)

Summary Sheet

Shelly E. Weaverdyck, PhD
Page 2 of 4

Difficulty arranging objects in space

Language impairment:

Difficulty understanding and producing speech

Difficulty reading and writing

Difficulty understanding what is being read, when can read

Insight impaired

Judgment impaired

Disorientation

Concentration impaired

Abstract processing impaired

Attention impaired

Sense of time impaired

Ability to analyze, plan, organize impaired

No sensory loss (though may occur with normal aging)

No focal deficits

No disturbance of consciousness

Person becomes increasingly dependent on environment throughout course

EMOTIONAL CHANGES

Depression throughout course, especially in early stages

Emotional lability (switch quickly from one emotion to another)

Less expression of emotional intensity and switching in later stages

BEHAVIORAL CHANGES

Get lost occasionally in early stages; increasingly often throughout course

Loses objects occasionally in early stages; increasingly often throughout course

Distressing behaviors usually triggered by anxiety, confusion and

misinterpretation of environment in middle stages

Distressing behaviors usually triggered by physical pain and discomfort in later stages

Gait and physical movements preserved until later stages

Incontinence only in later stages

Hallucinations when they occur, occur in later stages

INTERVENTIONS: Non-medical

Assess individual regularly over time as dementia progresses

Modify expectations and intervention as change occurs

Express warmth and affection for person, verbally and nonverbally

Respect person as adult; avoid treating person as a child

Stay calm and help the person feel relaxed

Compensate for the person's cognitive impairment to help person feel good and comfortable and to prevent fatigue and embarrassment

ALZHEIMER'S DISEASE (AD)

Summary Sheet

Shelly E. Weaverdyck, PhD
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Assess and modify environment, caregiver interactions and daily routines over time throughout course

Maintain appropriate stimulation that engages person
Avoid meaningless or confusing stimulation

Use touch as appropriate when communicating

Simplify daily routines and tasks

Provide information through cues in environment and when communicating

Ensure cues are understandable to person

Avoid arguing with the person

Address person's feelings and then distract when person engaged in distressing behavior

Explain to person what caregiver is doing and intends to do

Use concrete requests and concrete cues

Compensate for sensory changes that occur with normal aging

MEDICAL TREATMENTS

Cure unknown

Reduce loss of acetylcholine (inhibit acetylcholinesterase)
Cognex, Aricept, Exelon, Reminyl
Most effective in mild-moderate stages

Memantine (regulates activity of glutamate)
Can be effective in severe stages (for persons with MMSE score of 3-14)

Cholinergic medications for behavioral symptoms

Antioxidants

Anti-inflammatory agents

Neurotrophic compounds

Anti-amyloid deposition

Vitamin E in high doses (only under doctor's care) (effectiveness is controversial)

To extent AD associated with cardiovascular risk factors, can prevent by reducing cardiovascular risk factors: Exercise, Diet, cholesterol-lowering medications (statins) such as Lipitor

COMMENTS

In 1984 criteria for clinical diagnosis created

Red flags that suggest a disorder is probably not AD:

- Onset before age 60 years
- Sudden onset
- Rapid progression
- Symptoms that do not occur in the order of typical AD stages
- Behavior changes or hallucinations occur much earlier than memory impairment
- Incontinence occurs before later stages

ALZHEIMER'S DISEASE (AD)

Summary Sheet

Shelly E. Weaverdyck, PhD
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Seizures occur before later stages
(Exception: Downs may cause earlier seizures)
Abnormal neurological symptoms (impaired gait, falls, weakness) occur
before later stages

RESOURCES

<http://www.ninds.nih.gov/disorders/alzheimersdisease/alzheimersdisease.htm>

(National Institute of Neurological Disorders and Stroke NINDS)

<http://www.alzheimers.org> (Alzheimer's Disease Education and Referral Center
ADEAR)

<http://www.alz.org> (Alzheimer's Association)

<http://www.med.umich.edu/madrc/> (Michigan Alzheimer's Disease Research
Center MADRC)

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DEMENTIA WITH LEWY BODIES (DLB)

A Summary Sheet of Information and Intervention Suggestions With an Emphasis on Cognition

By Shelly E. Weaverdyck, PhD

AD refers to Alzheimer's Disease

CHARACTERISTICS

Brain Disorder

Most obvious symptoms: impairment in cognition, movement, behavior

Progression: increasing severity of symptoms over time (a progressive dementia)

Onset: age 50-70, usually around 55 or 65

Duration: shorter than AD and shorter life expectancy than AD

Cause unknown

Cure: no cure at this time, but there is treatment to reduce symptoms

Diagnosis verified at autopsy

Very common cause of dementia (20% of all dementia cases in United States; second most common)

About 66% of people with DLB also have cognitive symptoms of AD

Course: fluctuating (alternating periods of higher and lower functioning) with an overall decline over time, spontaneous improvement and decline, more rapid course than AD

Increased sensitivity to some medications

Named after F. H. Lewy, a German neurologist who in 1912 found the pathology (Lewy Bodies) in the brain stem

Other names: Lewy Body Dementia (LBD), Cortical Lewy Body Disease (CLBD)

NEUROPATHOLOGY

Lewy bodies inside brain cells

Acetylcholine reduction

Dopamine reduction

Neuritic plaques and neurofibrillary tangles (when AD present, as it frequently is)

LOCATION OF CORTICAL BRAIN CHANGES

Cortical refers to the cortex (i.e., the outer layer) of the brain

Changes (pathological abnormalities) occur in the cortex and in internal (subcortical) structures of the brain

Changes (pathological abnormalities) occur on both sides of the brain

Cortical brain structures affected:

Parietal lobe

Occipital lobe

Temporal lobe

Subcortical changes disrupt frontal lobe functioning

DEMENTIA WITH LEWY BODIES (DLB)

Summary Sheet

Shelly E. Weaverdyck, PhD
Page 2 of 4

Brain stem (subcortical): disrupted consciousness, REM sleep, and sleep behavior)

Limbic cortex (subcortical): disrupted emotions

COGNITIVE CHANGES

Fluctuations: good periods, then periods of more impairment, then good periods

Memory less affected than in AD (memory loss more evident in later stages)

Visuospatial: difficulty recognizing distance between objects and from self and difficulty arranging objects in space

Attention impairment (fluctuates)

Frontal-subcortical skills impaired

Logic based on wrong premise (paranoia with a detailed, perhaps plausible rationale)

Problem solving impaired early in course

More insight than in AD, often

Sensitivity to noise, sometimes

Disinhibition, sometimes

Inappropriate sexual behaviors, sometimes

Manipulation and controlling behaviors, sometimes

May sense or know hallucination isn't true, but is still emotionally engaged

EMOTIONAL CHANGES

Mood shifts: may be rapid;

Unexplained and unpredicted anger or aggression, sometimes

Depression is common

BEHAVIORAL CHANGES

Hallucinations: particularly visual, emotionally engaging; begin early in course; well formed, detailed

Parkinson symptoms: slowed movements (bradykinesia); balance impairment; coordination impairment; rigidity; stooped posture; shuffling walk; some people have a tremor

Falls

Paranoia

Delusions

Syncope

Transient loss of consciousness (unexplained)

REM Sleep disturbance: act out dreams (can begin years or decades before dementia symptoms appear; sleep gets better as dementia symptoms get worse)

Good days (weeks) bad days (weeks)

Most persons are not aggressive, but many persons with dementia who are aggressive have DLB. Non family caregivers often report particular fondness for the person between episodes.

DEMENTIA WITH LEWY BODIES (DLB)

Summary Sheet

Shelly E. Weaverdyck, PhD
Page 3 of 4

INTERVENTIONS: Non-medicinal

Use visuospatial interventions:

economy of movement (move minimally, gesture minimally, organize so most caregiver movement is out of sight of person)

watch for person's reaction and adjust caregiver response

reduce clutter and unnecessary objects

slow down

approach from front

Maintain flexible and accurate expectations of person (expect fluctuations)

Address unpredictability of cognition and behaviors

Do difficult tasks (e.g., bathing) when person is in higher functioning period

Don't argue

Ask carefully (maybe indirectly) about hallucinations

Counsel to find way of tactfully communicating when hallucination isn't true

Counsel person using insight that may be intact until later stages

Reduce noise

Walk to keep legs from going numb and to reduce rigidity

Prevent falls

Soften environment to reduce risk of injury from falls

Monitor nighttime sleeping behavior

Monitor for mood shifts and unexpected aggression

Constant 1:1 to prevent unpredictable aggression

Treat depression

Remember what is lovable about this person

Support family/caregivers (guilt, doubt, frustration)

May need to move to long-term care setting earlier than in AD (family fatigue, family not accurate in perception, family guilt)

Address uncertainty and guilt of caregiver

Educate/remind caregiver course is unpredictable

Educate/remind caregiver DLB can look like it's not dementia, though it really is

Tell families/caregivers:

Description of the course of DLB

Remember it is dementia even when person appears normal or unlike a person with AD (e.g., memory for details)

Fluctuations

Expectations can be too high (or too low some days)

Unpredictable behavior and cognition

Easy to feel guilty

DEMENTIA WITH LEWY BODIES (DLB)

Summary Sheet

Shelly E. Weaverdyck, PhD
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MEDICAL TREATMENTS:

Cure unknown

Reduce loss of dopamine (Parkinson medications)

Reduce loss of acetylcholine (AD medications)

Anti-psychotic medications (neuroleptics) for hallucinations and delusions may cause severe rigidity or death (neuroleptics lower dopamine levels)

Unusually sensitive response to sedatives (extreme responses)

Medications that treat behaviors and hallucinations may make the Parkinsonian symptoms worse; medications that treat the Parkinsonian symptoms may make the behaviors and hallucinations worse. Dosages must constantly be monitored and adjusted.

COMMENTS

In 1996 consensus criteria for clinical and pathologic diagnosis created and have since been updated.

Kosak detected Lewy Bodies in cortex at autopsy in 1984 with new stain (dye)

Lewy bodies are pink abnormalities that darken over time, inside the cell

Often misdiagnosed as: Dementia with psychosis, with agitation, with hallucinations, or similar behaviors;
or, early in the course, as a mental illness

RESOURCES

<http://www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm> (National Institute of Neurological Disorders and Stroke NINDS)

<http://www.lewybodydementia.org> (Lewy Body Dementia Association, Inc.)

<http://www.alzheimers.org> (Alzheimer's Disease Education and Referral Center ADEAR)

<http://www.alz.org> (Alzheimer's Association)

<http://www.med.umich.edu/madrc/> (Michigan Alzheimer's Disease Research Center MADRC)

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FRONTOTEMPORAL DEMENTIA (FTD)

A Summary Sheet of Information and Intervention Suggestions With an Emphasis on Cognition

By Shelly E. Weaverdyck, PhD

AD refers to Alzheimer's Disease.

CHARACTERISTICS

Brain disorder

Most obvious symptoms: behavior and personality changes

Progression: increasing severity of symptoms over time (a progressive dementia)

Onset: insidious; age 40-65 usually, (average age about 60)

Duration: slightly longer than for AD

Cause unknown

Cure: no cure at this time, but there is treatment to reduce symptoms

Diagnosis supported by structural imaging (e.g., CT, MRI) or functional imaging (e.g., PET, SPECT) of person's brain before death

Fairly common cause of dementia (10-15% of all dementia cases)

About 140,000 – 350,000 people in United States have FTD

Only known risk factor is family history

May be hereditary in 38-60% of cases (chromosome 17, or less often chromosome 3)

Course: behavior and personality changes are first and most obvious symptoms throughout course. Course varies with individual. Slower course than AD, usually.

Name is based on location of neuropathology. A variety of diseases cause FTD.

NEUROPATHOLOGY

Varies with type/cause:

(e.g., Pick bodies are found in 20% of cases at autopsy)

Atrophy (i.e., loss) of brain tissue; cell death

No neuritic plaques

No neurofibrillary tangles

No Lewy bodies

No significant changes in Acetylcholine

No changes in EEG even in late stages

LOCATION OF CORTICAL BRAIN CHANGES

Cortical refers to the cortex (i.e., the outer layer) of the brain

Changes (pathological abnormalities) occur in the cortex and in internal (subcortical) structures of the brain

Changes (pathological abnormalities) occur on both sides of the brain

FRONTOTEMPORAL DEMENTIA (FTD)

Summary Sheet

Shelly E. Weaverdyck, PhD
Page 2 of 5

Cortical brain structures affected:

- Frontal lobe
- Temporal lobe (anterior)

COGNITIVE CHANGES

Preserved in early part of course:

- visual & auditory perception
- spatial perception
- orientation
- praxis
- memory
- time orientation

Preserved in later part of course:

- spatial orientation (e.g., don't get lost as often as do persons with AD)

Insight impaired early in the course

Impairment in speech: very obvious symptom; impaired in early part of course; increasingly impaired throughout course:

- Reduced spontaneity
- Fewer words used
- Repetition of limited variety of words, phrases, themes
- Clichés used; difficulty individualizing speech to situation
- Echolalia (person says words or phrases she/he just heard)
- Perseveration (person repeats an action or speech)
- Mutism (lack of speech) eventually, often
- Comprehension often less impaired than speech

Impaired earlier in the course than in AD, with increased impairment over time:

- Perseveration
- Mental rigidity and inflexibility
- Concentration impaired
- Distractibility
- Impulsivity
- Reasoning impaired
- Judgment impaired
- Abstract thinking impaired
- Lack of concern for accuracy
- Initiation impaired
- Sense of time impaired
- Ability to empathize with others impaired
- Ability to monitor self impaired
- Ability to adapt impaired

FRONTOTEMPORAL DEMENTIA (FTD)

Summary Sheet

Shelly E. Weaverdyck, PhD
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EMOTIONAL CHANGES

- Depression
- Anxiety
- Excessive tearfulness
- Suicidal thoughts
- Delusions
- Hypochondriasis
- Bizarre somatic preoccupation (focus on own body)
- Emotional unconcern (indifference, remoteness, lack of empathy, apathy, blank facial expressions)
- Inappropriate emotional expressions:
 - Laugh instead of cry
 - Exaggerated expression
 - Switch quickly (lability)

BEHAVIORAL CHANGES

- Mood and behavior changes early in the course:
 - Personal awareness impaired (poor personal hygiene and grooming)
 - Social awareness impaired (lack of social tact, petty crimes)
 - Disinhibition (inappropriate sexual behavior, physical aggression, inappropriate laughter and joking, restless pacing)
 - Lethargy
 - Family and work ignored or get less attention
 - Incontinence
- Changes vary with individuals
 - Some quiet and withdrawn; Some disinhibited and disruptive
 - Some lethargic; Some hyperactive
- Repetitive behaviors (e.g., wandering, clapping, singing, dancing)
- Ritualistic behaviors (e.g., hoarding, cleaning)
- Fixations and obsessions
- Impulsivity
- Hyperorality (e.g., overeating, food cravings, excessive smoking, excessive alcohol consumption, putting objects in mouth)
- Exploring and handling objects in environment excessively or inappropriately
- Sleep increase in time and increased drowsiness
- Movement rigid in later part of course, sometimes

INTERVENTIONS: Non-medicinal

- Assess individual for abilities and functions (do not generalize FTD symptoms)
- Acknowledge that comprehension is usually better than expression of language:
 - Talk to person directly
 - Don't talk about person in front of her/him
- Avoid giving unintended cues or information

FRONTOTEMPORAL DEMENTIA (FTD)

Summary Sheet

Shelly E. Weaverdyck, PhD
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Orient to time

Structure person's time with activities and events

Emphasize consistency; and predictability in:

Schedule of events and daily routines (in time, duration, and order)

Who is providing care (same caregiver each time)

The way a task is done (e.g., order of task steps, same task objects)

Where events and activities take place

Environment (e.g., avoid changing rooms or furniture)

Methods of communication

When communicating:

Increase non verbal forms of communication

Get and keep the person's attention

Give time to start action

Keep information and requests concrete

Use few words, short words and phrases

Use most important words first

Use music, singing, rhythm to help person move and to shift attention

Be clear and respectful with requests; minimize emotional energy and content of request

Use speech therapy that relies on intact parietal lobe functions rather than impaired frontal lobe functions (e.g., use nonverbal stimuli and methods of communications, music, rhythm, fewer lengthy explanations or questions)

shift from one thought or activity to another slowly; give time

Address social behaviors of person:

distress of caregiver regarding behaviors (embarrassment, concern)

impact on children and coworkers

community awareness, support, law enforcement

Support family and caregiver

Address anger

Educate/remind caregiver FTD is a brain disorder

Prepare for employment and financial implications

Prepare for future care

Tell caregiver and family:

Explain course of FTD

Expectations must match individual abilities

Comprehension is usually less impaired than speech

Be predictable: minimize change, do the things the same way each time

MEDICAL TREATMENTS

Cure unknown

Increase serotonin for repetitive and obsessive behaviors

Cholinesterase inhibitors do not help, since Acetylcholine is not reduced

FRONTOTEMPORAL DEMENTIA (FTD)

Summary Sheet

Shelly E. Weaverdyck, PhD
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COMMENTS

In 1994 consensus criteria for clinical and pathologic diagnosis first created and have since been updated.
Pick bodies were first described in a patient by Arnold Pick in 1906.
Often misdiagnosed as AD
May be associated with Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis)

RESOURCES

<http://www.ninds.nih.gov/disorders/picks/picks.htm> (National Institute of Neurological Disorders and Stroke NINDS)
<http://www.FTD-Picks.org> (Association for Frontotemporal Dementias (AFTD))
<http://www.alzheimers.org> (Alzheimer's Disease Education and Referral Center ADEAR)
<http://www.alz.org> (Alzheimer's Association)
<http://www.med.umich.edu/madrc/> (Michigan Alzheimer's Disease Research Center MADRC)
Radin, L & Radin G (Eds) What if it's Not Alzheimer's? Prometheus Books, Amherst, New York 2003 (More info: phone 716-691-0133, ext. 207).

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SLIPSHEET

Session 2: Understanding Brain Changes in Dementia

Lynn LaRue Chenoweth and Beth Spencer
With Caring Sheets by Shelly E. Weaverdyck

Interactive Training Strategies

- Mini lectures with discussion questions
- Video clips of Irene Porter at mealtimes
- Case study of Mrs. Brock for practicing cognitive skills
- Styrofoam brain model exercise – Bessie story
- Powerpoint slides and photographs for discussion

SUGGESTIONS FOR CONDUCTING SESSION 2

Understanding Brain Changes in Dementia

The goals of this session are:

- To teach staff about the different kinds of memory and how dementia impacts them.
- To increase staff understanding of the structure and organization of the brain.
- To increase staff awareness of the relationship of brain changes to the challenging behaviors and declining cognitive skills that impact their ability to care for persons with dementia.
- To teach staff the hallmarks of brain change that occur in Alzheimer's disease.

Introduction

Our brains are the resource for all that we do at any given moment in time. Our brains allow us to make sense of our environment, allow us to see, hear, smell, taste, and feel through touch. Our brains enable us to walk, talk, and learn, to remember the past, plan for the future, problem-solve, and organize our movements. When a person's brain is assaulted by a progressive and irreversible brain condition such as Alzheimer's disease, the person's ability to live a normal, productive life slowly declines. Eventually, that person can no longer do many of the things once taken for granted such as bathing, dressing, and feeding him or herself.

We are defined to a great extent by our ability to respond and function within our environment. This ability is dependent on the health of the brain, the body, and the brain-body connection at any given

time. Our perception of our environment, how we relate to and function within the environment, our perception of self and others, our physical and emotional health, all depend on the health of our brains.

We've learned from experience that the quality of our work and our staff's work is much improved by an understanding of the brain and its relationship to a person's ability to function. When staff understand the dementia-related changes, they are better able to adapt their approaches when giving care. Understanding brain changes also helps staff to accept that challenging behaviors are not intentional. We have found that knowing this information helps to reduce some of the frustration staff experience.

Sessions 1 and 2 lay the groundwork for all the other training sessions in this manual. We strongly encourage you to take the time to work through these initial sessions in detail with staff before moving on to ADLs or problem-solving strategies for challenging behaviors.

This session is comprised of three sections with accompanying exercises or video vignettes:

- A brief overview of different kinds of memory with discussion questions
- Introduction to the structure of the brain
 - Vignettes on the DVD that illustrate the relationship of brain structure to behavior in a person with dementia.
 - Case study to practice identifying cognitive skills and dysfunctions
- The brain and Alzheimer's disease
 - The story of Bessie and David
 - Brain model exercise
 - The four hallmarks of Alzheimer's disease

- Caring Sheets #1, #2, #19

The three Caring Sheets included in this session were written by Shelly Weaverdyck. They can be used as handouts, as background preparation for the trainer, or both. The full set of twenty-four Caring Sheets can be found at <http://www.lcc.edu/mhap/>

A brief overview of different kinds of memory

Many different models of memory have been developed. These are still hypotheses as there is a lot that scientists and psychologists do not understand yet about how memory works. Still, they have learned a great deal in the past twenty-five years and **it is quite helpful to understand a few basic points: We use various kinds of memory as we function in daily life. These appear to lodge in several areas of the brain and can be affected differentially with dementia.**

The different types of memory will be referenced throughout this manual. In Session 1, we have already presented some of the normal age changes in memory and thinking. These will not be reviewed here but can be helpful to review with staff as you discuss how memory works.

We have included a few references for trainers who would like to read more about this area; these include writings for lay people as well as more technical materials for professionals (Attix and Welsh-Bohmer, 2006; Stern and Fogler, 2005; Zgola, J.M., 1999; Schacter, D.L., 1996). Be aware that different professional groups have categorized and named memory in different ways; some talk about implicit and explicit memory, coding and retrieval. We will talk about working memory, sensory memory, short-term or recent memory, long-term memory, and procedural memory. Our discussion questions and mini-lecture are quite simplistic, but will help staff begin to understand the basic points above. We have

included a few good quotations from experts in the field.

An important point to make is that everyone's memory is individual throughout life – we all have areas of strength and weakness – and this is true of people with dementia as well, both because of lifelong traits and the dementia. We have included discussion questions in the outline to help staff think about each of these areas. There is a little more elaboration in the *Outline*. The types of memory that are discussed there are:

Working memory, the very short-term memory one uses to hold onto a phone number before dialing. Working memory is usually not as strong in older adults as in younger people and it can be quite impaired in some people with dementia.

Sensory memory, what we see, hear, feel, smell, and taste. Most sensory sensations do not go into long-term memory.

Short-term or recent memory, the kind of memory loss that is so evident in those with Alzheimer's or some other dementias. Many times information does not appear to be making the transfer to long-term memory.

Long-term memory, where we store our memories of earlier life. In people with dementia the long-term memory usually remains more intact than short-term for awhile.

Procedural or motor memory is “the mechanism by which we acquire habits and learn skills that we eventually do automatically.” (Zgola, p. 97)

It is important to point out to staff that procedural memory is located in a different part of the brain from other types of memory. The part of the brain where procedural memory is stored is thought to be spared until the advanced stages of dementia. Also, it is important to

understand that procedural memory and learning rely on repetition. Often people with dementia can learn new tasks with enough repetition. However, when tasks are taken away, when people stop practicing, the ability can be lost.

Procedural memory will be discussed again in Session 5 in relation to helping individuals with dementia with their ADLs.

Introduction to the structure of the brain

Teaching staff about the structure of the brain helps them understand the behaviors they see in a new light. There are some discussion points for you to make about brain structure. The exercises in this session were designed to help staff understand and practice some of the information about brain structure, which can seem very technical if taught without exercises.

At the end of this session, we have included three Caring Sheets written by neuropsychologist, Shelly E. Weaverdyck, Ph.D. These Caring Sheets were written in language that is accessible to direct care staff and families. Use the Caring Sheets either

- As handouts, or
- As the basis for mini-lectures on the brain.

Caring Sheet #1 – The Healthy Brain and Cognition describes the way the brain is structured and what functions the various parts of the brain are responsible for.

Caring Sheet #2 – Brain Changes & the Effects on Cognition describes the changes that can occur with dementia and how different parts of the brain are implicated in the behavior changes we see.

Caring Sheet #19 – Intervention Suggestions for Frontal Lobe Impairment describes the type of behaviors we see in individuals who have damage to their frontal lobes and suggests a number of interventions to use with these people.

Using the Caring Sheets in conjunction with the Irene Porter video clips or the Brain Model Exercise or both will help staff understand the relationships of brain change to the behaviors we see in our clients or residents with dementia.

Video vignettes of Irene Porter: Mealtime experience

These six very short video clips, found on the DVD, illustrate problems that Irene Porter typically has eating her meals. Her problems are a result of brain changes that have occurred because of probable Alzheimer's disease. These are a very good way to help staff begin to analyze the kinds of difficulties that individuals are having in more detail and to relate these difficulties to specific changes in the brain.

Instructions

Provide staff with the worksheet to fill in as they watch the video clips before engaging in a discussion. The Irene Porter at Mealtime Worksheet is on the CD. Because the clips are very short, it makes sense to watch them all before discussing. Below is an example of video clip #1.

Analyzing the video clips: Instruct staff to view the clips with 3 questions in mind:

- What problem(s) is Irene having?
- What part of the brain is involved with this problem?
- What strategies does the staff member use to enable Irene to be more successful?

Clip #1

- Brain Changes: Frontal Lobes
- Problem: Irene does not recognize that she has eaten all of the strawberries and the bowl is empty.
- Strategy used: Have staff discuss this after watching the short video clip.

Case study of Mrs. Brock

This case study was developed to use with staff to help them apply information about the brain to an actual situation. The Case Study: Mrs. Brock's Brain and Behavior,

the Worksheet for Case Study, and the Cognitive Skills List are on the CD.

It is important for staff to have some experience in interacting with persons with dementia before they attempt this case study. The discussion questions that accompany the case study are probably too difficult to use with new staff, but should work quite well with more experienced staff. We have developed a Cognitive Skills List to accompany the case study. This seems to help staff make the connections between Mrs. Brock's difficulties and some of the brain changes.

Instructions for use of case study:

- Give each staff member a copy of the case study and the Cognitive Skills List.
- Follow normal case study instructions.
- Debriefing of case study: On the CD there is a Case Study Worksheet with possible answers to the case study questions. These are by no means all-inclusive; there are many other possible answers that staff may come up with.

The brain and Alzheimer's disease: Bessie's story

This exercise uses one or more Styrofoam head models to help staff learn and practice some important structures of the brain and relates it to one woman's story as a way to try to humanize this information. Below are instructions for making a Styrofoam brain model.

Brain model instructions

It does not take long to assemble the brain model and once completed can be used over and over. There are step-by-step photographs for making a brain model on the CD. This is an opportunity to impress staff with your creativity!

Materials needed

- Styrofoam Wig Stand (head) – can be found in Beauty Supply stores, \$2.00 - \$4.00 each.

- Permanent Markers – Black – Fine to Medium Point
- Permanent Markers – Colors – Fine to Medium Point (Optional).
- Colored Pencils (Optional).
- Personal Items – scarf, boa or collar, hat, and buttons or other small, light-weight items for earrings.
- Solid wood board approximately 9" x 16" for mounting the Styrofoam head. Size of board can be smaller but heavy enough to keep light-weight brain model from tipping over during the presentation.
- Fabric to cover the baseboard.
- Scissors.
- Hot glue gun.

Assembly instructions (See photographs on CD.)

- Place brain model on the baseboard. Trace around the base of the Styrofoam head with marker. Remove the model.
- Apply glue with glue gun to the circle you have traced on the baseboard.
- Immediately position the brain model onto the glue. Press down firmly. Wait 2 – 3 minutes. Apply a second bead of glue around the base of the brain model. Let dry completely before continuing.
- Outline and label the lobes:
Frontal Lobes – black marker
Parietal Lobes – black marker
Temporal Lobes – black marker
Occipital Lobes – black marker
- Lightly color-code the interior of each pair of lobes.
- Glue on earrings (female model).
- Add facial features with colored pencils (optional) – eyes, eyebrows, lips, five-o'clock shadow (male model). Rubbing colored pencil into the surface of the model gives a rosy glow to female cheeks or an unshaven look to male cheeks.

- Dress your brain model with hat, boa, collar, scarf, or whatever else you have.
- Cover the baseboard with a piece of fabric so that it is not visible to your audience.
- Give your model a name. Personalizing the brain model maintains and reinforces our philosophy of person-centered dementia care. Below we will introduce Bessie's story – Bessie is the name we have given to our model. We've included photos and history of Bessie's life to make it more real to staff.

Bessie exercise

Materials needed

- Toothpicks
- File folder labels or other sticky paper to make cognition marker "flags." (See photo illustrations on the CD.)

Bessie's story

In the *Outline* is a brief biography of Bessie and David LaRue. On the CD are two photographs – one of their wedding day; another of Bessie as an elderly woman. Read the biography of them, show their photographs, and ask staff the discussion questions in the *Outline*.

Following the discussion, use the brain model of Bessie to talk about what lobes of the brain account for the behavior and cognitive changes in Bessie. You may want to focus on a single task such as dressing, bathing, or eating. Bessie's mealtime experience is used in the *Outline* as an example of how this can be done.

Strategies for addressing these behaviors will be addressed in Session 5. Here, the trainer's role is to help the staff make the connection between those invisible brain changes discussed earlier and changes in behaviors and declining cognitive skills.

You may also find the brain model helpful earlier, while you use the Caring Sheets to teach the basic structures of the brain.

The four hallmarks of Alzheimer's disease

Staff sometimes want to understand more about the changes occurring in the brains of individuals with Alzheimer's disease. While we talk about cognitive changes in different areas of the brain, this does not explain what is happening at a cellular level. This part of the session offers a simplified way to discuss the brain changes that happen when someone develops Alzheimer's disease.

On the CD are photographs of simple props you can use to illustrate the hallmarks of Alzheimer's disease in the brain. Use real props if you can, though you could show the photographs instead. A mini-lecture on each of the four hallmarks is included in the *Outline*.

Materials

- Photos of a normal brain and a brain with Alzheimer's disease.
- Illustrations of neurons with and without Alzheimer's disease.
- 3 oranges – small, medium and large.
- Tea strainer or medium-size strainer (rusty if possible).
- Twisted bundle of plastic straws.

The four hallmarks being presented and illustrated are:

1. **Atrophy or shrinkage of the brain.** An easy way to illustrate this is with three pieces of fruit. (See photograph on the CD).
2. **Neuritic plaque or "rust" in the brain.** This can be illustrated with a kitchen strainer. If you happen to have a rusty one or can put something on it to clog the holes, that will illustrate the point even better. (See photograph on the CD).
3. **Neurofibrillary tangles or starvation of the brain.** This can be illustrated with a bunch of twisted straws. (See photograph on the CD).
4. **Neurochemical deficiencies or low batteries.** Illustrate this with two cell phones.

Materials on the CD for this session:

Case Study: Mrs. Brock's Brain and Behavior

Case Study Worksheet

Cognitive Skills List for Case Study

Irene Porter at Mealtime Worksheet

Seventeen photographs illustrating exercises, brain models, and props

One photograph showing a normal and an Alzheimer's brain

One color illustration of different lobes and functions of the brain

Two photographs of Bessie at different times in her life

Illustration of a normal neuron and a neuron with neurofibrillary tangles

Illustration of a synapse

SESSION 2

OUTLINE FOR TRAINERS

Understanding Brain Changes in Dementia

How Memory Works

Introductory Comments

- We are going to begin learning about the brain with a discussion of how memory works. **It's important to remember that each of us is unique.** No two people have the same abilities and every person has some parts of their memory that work better than others.
- **Memory abilities change with normal aging to some extent,** but they are much more affected by the changes in the brain that happen with dementia – illnesses such as Alzheimer's disease.
- **There's a lot that is not known about how memory works yet.** And there are many different ideas about this among scientists and psychologists. This is just one version of how memory works in our brains.

Working memory is that very short-term memory one uses to hold onto a phone number before dialing or to remember your grocery list until you get to the store. Working memory is usually not as strong in older adults as in younger people and it can be quite impaired in some people with dementia.

Discussion questions

How well does your working memory work? Can you think of examples of trying to remember a piece of information until you completed some task? Is it frustrating when you can't remember?

Sensory memory is what we see, hear, feel, smell, and taste. Most sensory sensations

do not go into long-term memory. On the other hand, sensory memory is often the most powerful way to evoke some long-term memories. Pieces of music, smells, seeing or touching items from childhood are often extremely good triggers for memories for adults with dementia.

Discussion questions

Can anyone give us an example of a memory that comes to your mind with a particular song or a particular smell? How can we use sensory memory to develop pleasant activities for our clients or residents?

Short-term or recent memory is the kind of memory loss that is so evident in those with Alzheimer's or some other dementias. Many times information does not appear to be making the transfer to long-term memory. Other times, the person has a deficit in his or her ability to retrieve information from long-term memory. Usually it is with short-term memory that families first notice problems in a family member – a mother who no longer recalls the conversation she and her daughter had earlier in the day, or a husband who repeatedly asks his spouse when their company is coming.

Example: Can you remember what you had for breakfast today? What you did last night? People with short-term memory loss often cannot recall those types of memories.

Read quote:

Jitka Zgola, an occupational therapist and dementia expert writes, “[The cognitively impaired person] uses a mechanism that can drive those around her crazy – repeating a question over and over again. It is the same mechanism that we use to “carry” a telephone number in our head from the phone directory to the dial pad...We repeat it over and over until we have finished dialing, then we promptly forget it. This is exactly what a person with short-term memory loss does. She keeps the item in working memory until for some

reason she drops it. Sensing that it is gone, but unable to retrieve it herself, she asks for help by repeating the question.” (Zgola, p. 12)

Discussion questions

Who can give an example of someone we work with who has short-term memory impairment?

How do you think it makes people feel not to be able to hang onto important pieces of information?

Long-term memory is that memory bank where we store our memories of earlier life. In people with dementia the long-term memory usually remains more intact than short-term for awhile. But gradually long-term memories begin to fade as well. To some extent this may be a problem with getting the information out – it’s there in the brain, but the person can’t get to it without cues anymore.

Example: Mrs. Brown may no longer be able to tell you that she was born and raised in Mississippi, but if you point to a map of Mississippi or show her a photo of herself as a child, she may well be able to retrieve some details with the help of these cues.

Discussion questions

How are long-term memories important to us?

How can we help people recall those long-term memories that they may not be able to remember on their own?

Procedural or motor memory is “the mechanism by which we acquire habits and learn skills that we eventually do automatically.” (Zgola, p. 97)

Examples: Brushing our teeth or hair, setting the table, drying the dishes are all things we do automatically. When you first learn to do skills such as riding a bike or making a bed, they may not be easy for you because they involve a complex pattern of movement. However, once you have practiced riding a bike over and over,

it becomes easier, almost like a reflex. You don’t have to think about it – you do it automatically. Dressing, eating, and bathing are tasks that involve elements of procedural memory that we can learn to build on.

Procedural memory is located in a different part of the brain from other types of memory. The part of the brain where procedural memory is stored is thought to be spared until the advanced stages of dementia. Also, it is important to understand that procedural memory and learning rely on repetition. Often people with dementia can learn new tasks with enough repetition. However, when tasks are taken away, when people stop practicing, the ability can be lost.

Discussion questions

Can you think of some times during your work with individuals with dementia where you see their procedural memory kicking in?

Structure of the Brain

Trainer: Have your brain model ready and the Labeled Brain Illustration from the CD.

Let’s look at the unique structure of the brain to help us better understand the relationship between specific areas of the brain with Alzheimer’s disease and our ability to successfully accomplish what we call activities of daily living (ADLs).

In this illustration (Labeled Brain Illustration on CD) we see a brain stem, the cerebellum or ‘Little Brain’, and the cerebral cortex all of which makes up approximately 85% of the total weight of the brain. Looking at our model (remove the hat from the model you’ve made) you see that the brain has a right and left side. These right and left side hemispheres, as they are called, are mirror images of one another. They look alike, share many responsibilities, but also maintain their own identity for specific functions. The right

hemisphere, for example, helps a person to control the sensory and motor functions of the left side of the body; the left hemisphere helps a person to control sensory and motor functions of the right side of the body.

Example: A person who has experienced a stroke in the left hemisphere may have serious speech and language problems but can still sing the words of familiar songs. How can this be explained? The person's ability to speak is controlled primarily by a specific area found in the left hemisphere, the person's ability to sing is controlled primarily by a specific area found in the right hemisphere. In other words, the human brain has a unique pathway for singing and a different pathway for speaking.

Our Bessie model shows that the left hemisphere is divided into four distinct lobes, the **frontal, temporal, parietal, and occipital lobes**. Given the fact that our bodies are symmetrical, it should come as no surprise to find that the right hemisphere is also divided into four lobes, each a mirror image of its left-side counterpart. Thus, we can say that our brain is actually divided into four pairs of lobes. What's most interesting is the fact that Alzheimer's disease appears to be most attracted to three of these pairs, the frontal, temporal, and parietal lobes.

Summary The brain is a symmetrically structured organ having a right and left hemisphere, each a mirror image of the other. In turn, each hemisphere is divided into four lobes that mirror one another, the frontal, temporal, parietal, and occipital lobes. Many changes that David was seeing in Bessie's behavior and the decline in her ability to function were the results of changes occurring in three specific areas of the brain, mainly the frontal, temporal, and parietal lobes.

Trainer: Use Caring Sheets to further discuss the structure of the brain and what happens with dementia.

Video Vignettes of Irene Porter: Mealtime Experience

Instructions

Option 1: View and discuss each clip, one at a time. Have staff identify the strategy used in each scenario.

Option 2: Provide staff with the worksheet to fill in as they watch all of the video clips before engaging in a discussion. The Irene Porter at Mealtime Worksheet is on the CD.

Analyzing the video clips: Instruct staff to view the clips with 3 questions in mind:

- What problem(s) is Irene having?
- What part of the brain is involved with this problem?
- What strategies does the staff member use or would you use to enable Irene to be more successful?

The video clips illustrate problems that Irene Porter typically has eating her meals. Her problems are a result of brain changes that have occurred because of probable Alzheimer's disease.

Clip #1

- Brain Changes: Frontal Lobes
- Problem: Irene does not recognize that she has eaten all of the strawberries and the bowl is empty.
- Strategy: The staff member recognizes that she wants more and provides it.

Clip #2

- Brain Changes: Frontal Lobes
- Problem: Irene loses her concentration, forgets she is eating, and has difficulty getting started again without assistance.
- Strategy: Tapping on the bowl and a gentle touch both help focus her attention on the task at hand. Using different senses can be helpful.

Clip #3

- Brain Changes: Frontal Lobes
- Problem: Irene wants to clean up the table. When the staff member intervenes, Irene resists in an effort to maintain control of what she wants to do.
- Strategy: The staff member gives her a dishcloth which helps her procedural memory kick in. Irene begins to clean the tablecloth rather than trying to pull it off.

Clip #4

- Brain Changes: Temporal Lobes
- Problem: Irene is unable to verbally communicate her wants and needs.
- Strategy: The staff member tries repetition.

Also note the following in this clip:

- Brain Changes: Frontal Lobes
- Problem: Irene is having trouble following simple one-step directions.

Clip #5

- Brain Changes: Parietal Lobes
- Problem: Irene is having difficulty using her spoon to scoop up strawberries from her bowl.
- Strategy: The staff member supports Irene's efforts using a second spoon.

Also note the following in this clip:

- Brain Changes: Frontal Lobes
- Problem: Irene is easily distracted, unable to stay on task.
- Strategy: The staff member taps her spoon on the dish to redirect Irene to the task of eating from the bowl.

Clip #6

- Brain Changes: Parietal Lobes
- Problem: Irene is having difficulty with depth perception and spatial relationships. She sees the food on the plate in front of her but is unable to locate it when reaching for it.
- Strategy: The staff member repositions and turns the plate to help her locate it.

Also note the following in this clip:

- Brain Changes: Frontal Lobes
- Problem: Irene may not recognize the food for what it is and what to do with it.

Things to point out to staff:

- The staff member is using serving dishes in contrasting colors; Irene's favorite color is yellow.
- The staff member has eliminated the placemat and kept the center of the table clutter-free.
- The staff member has seated herself on Irene's right side. Irene tends to see and reach for things on her right. This makes it important to keep the right side clear of unessential items and to pay attention to who is seated on the right.
- All of these strategies help to address some of Irene's persistent behaviors and cognitive decline.

Definition of Cognitive Skills

Trainer: Use powerpoint slides or handout to talk about these.

Cognitive skills include

- Thinking,
- Remembering,
- Problem solving,
- Finding the words to express thoughts,
- Understanding what others say,
- Getting started on a task,
Example: The ability to sit down to a meal and know how to begin the task of eating.
- Controlling impulses,
Example: The urge to hit someone.
- Reading,
- Following directions,
- Decision-making,
- Using good judgment,
Example: Knowing what clothing is appropriate for the weather.
- Planning,

- Analyzing,
- Adapting to new situations.
- **Cognitive skills indicate the brain's ability to process and respond to information received from our environment – what we see, hear, taste, smell, and touch.**
- **Different cognitive skills are found in different areas of the brain.** Sometimes one part of the brain is relatively undamaged, while another area has significant damage. So some skills may remain strong, while others are impaired.
- **Every person with dementia has slightly different brain changes.** No two people have the same cognitive skill levels to start with and this is true with dementia as well.

Trainer: Use the Case Study of Mrs. Brock here.

The Brain and Alzheimer's disease: Bessie's Story

Introductory story

I would like to introduce you to Bessie and David LaRue. (Use photograph.) This is a picture of them taken on their wedding day. Their life story is a tapestry beautifully woven with memories of a life-long partnership. They have developed a love and respect for one another that seems impenetrable. David has always adored Bessie for her sense of humor, "gift of gab," limitless energy and patience, generosity, caring spirit, and her insatiable love for family.

Ten years ago their life together could still be described as a real life fairy tale. David was enjoying retirement; Bessie was continuing to take pride in her role as a loving wife, homemaker, and David's best friend. Shortly after their 50th wedding anniversary, Bessie began experiencing difficulties staying focused on daily

household tasks such as the laundry, house cleaning, and preparing even the simplest meals. Routine tasks such as paying the bills on time, keeping the checkbook balanced, shopping, keeping the family calendar updated became challenging. Bessie lost interest in her favorite hobbies: gardening, quilting, playing the piano, and entertaining friends. Those core qualities that David so admired in Bessie, the essence of who she had always been, were fading. (Use photograph of Bessie as an elderly woman.)

Discussion questions:

What were the core qualities that David admired in Bessie?

What were some of the early signs and symptoms of brain changes that David noticed in Bessie?

Eventually Bessie was diagnosed with probable Alzheimer's disease. Over time the symptoms related to Bessie's disease became more debilitating. There were frequent mood swings and nighttime sleep disturbances. Bessie became more confused, anxious, and withdrawn much of the time. The tasks of bathing and dressing became more challenging. Meal times with David also became challenging. Bessie began having difficulty recognizing food and knowing what to do with it. She began having difficulty using eating utensils and figuring out the steps involved in picking up and drinking coffee from a cup.

Bessie's short-term memory had become very impaired; her attention span had become quite short. Outbursts of anger were becoming more frequent as she became less able to communicate her wants and needs. Control had become an issue for Bessie. She still valued her independence and reacted aggressively when someone tried to help her.

Discussion question

What changes in Bessie's behavior and cognitive skills made caregiving so challenging for David?

David made the decision to move Bessie to a long-term care facility because he could no longer cope with the overwhelming responsibility of providing for Bessie's personal care and safety. He had also become more focused on Bessie's disease and no longer able to recognize those core qualities that he had embraced for so many years.

David realized that he didn't fully understand what was happening in Bessie's brain during the course of her Alzheimer's disease and how that related to the changes in her behavior and the inability to take care of her self independently. He wondered if Bessie's new caregivers would have a better understanding than he did. He sincerely hoped that their knowledge would enable them to provide the level of care and quality of life for Bessie that he could no longer do on his own.

Discussion questions

What were David's primary concerns regarding his wife and his decision to move her to a long-term care facility?

What are some other concerns that families have when they choose to involve professional health care workers in the care of their family member?

David reports that mealtime isn't very pleasurable any more with Bessie. They used to enjoy meals together while listening to their favorite radio shows: Jack Benny, Amos'n Andy, Fibber Magee and Molly. Now Bessie either acts like she doesn't hear the radio at all or gets very upset during what used to be her favorite part of the shows, the jokes and laughter. David has made a list of his observations of Bessie during mealtime that he hopes will be helpful to the staff:

- Seldom expresses being hungry anymore.
- Doesn't remember having just eaten a meal.
- Difficult getting Bessie to come to the dining room for a meal.
- Frequently spills her milk when she reaches for the glass.
- Appears to have forgotten how to use a fork.
- Tries to scoop up food with her knife.
- Pushes food off the edge of her plate.
- Gets up frequently during the meal.
- Often confused about time and place for meals.
- Objects to being redirected.
- May accuse someone of stealing her food.
- Stares at the food, unable to get started.
- Unable to continue the process of eating without reminders.
- Doesn't always seem to remember to chew and swallow.

Trainer: Have staff use the brain model of Bessie at this point.

Staff will pin cognition markers in the appropriate lobe areas as they are discussed.. This hands-on experience will help enhance staff's understanding of the connection between brain changes, behaviors, and cognitive challenges they see in persons with probable Alzheimer's disease.

The Four Hallmarks of Alzheimer's Disease: Understanding What Changes Take Place in the Brain

- A diagnosis of Alzheimer's disease is confirmed when a pathologist examines brain tissue under a microscope after the person dies. There is no standard medical procedure at this time to diagnose Alzheimer's disease or other related dementia while a person is still alive, although specialists are over 90% accurate most of the time.
- When a brain with Alzheimer's disease is examined, the pathologist discovers significant changes
 - o in the size of the brain,
 - o in the appearance of brain cells,
 - o and evidence of low levels of a chemical necessary for transmitting messages from one brain cell to another.
- These changes are commonly referred to as the Four Hallmarks of Alzheimer's Disease.

1. Atrophy = shrinkage

The first hallmark of Alzheimer's disease seen by the pathologist is changes in the weight and size of the brain.

Trainer: Show photograph comparing a healthy brain and a brain with Alzheimer's disease.

In this illustration you are looking down at the top of a healthy brain, the cerebral cortex. The surface appears firm and compact. This is a healthy brain and weighs approximately 1400 grams or 3 pounds. In this second illustration, the brain has obviously undergone changes, causing the surface to become more spongy and less compact. This diseased brain will probably weigh only 900 to 1000 grams or a bit over 2 pounds, a loss of one third of its original weight.

Trainer: Show three oranges of different sizes or photograph of three oranges.

This first hallmark of Alzheimer's disease can be remembered by visualizing these 3 oranges. The first orange represents a normal brain weighing approximately 3 pounds. The second orange is smaller and represents the brain with Alzheimer's, weighing approximately 2 pounds. The smallest orange represents the brain with Pick's disease, another progressive brain disease. This brain may weigh no more than 1.5 pounds.

Summary: Atrophy describes the change in the weight and size of a brain with AD. The question is: Why is the brain shrinking?

2. Neuritic plaque = rust

The second hallmark of Alzheimer's disease seen by the pathologist is changes on the outer surface of many brain cells.

Trainer: Show illustration of a brain cell.

Here is an illustration of a brain cell, sometimes called a neuron. It looks like a kite with a tail. The surface of a neuron acts as a filter or strainer that allows food products to enter into the cell and allows waste products to move out of the cell – in much the same way that the human body functions: food in – waste out. Keeping the surface of brain cells free of debris is very important to maintaining the health of the cells.

However, in Alzheimer's disease, for reasons not clearly understood, the surface of many brain cells begin to attract an amyloid protein and other debris much like an old metal strainer attracts rust.

Trainer: Show a strainer (rusty if possible) or photograph with strainer and straws.

The amyloid protein (rust) clogs the surface of the cell and interferes with its ability to absorb nutrition. Nutrients can't enter the cell and waste products cannot exit. Eventually the cell dies.

Summary: Neuritic plaque refers to the amyloid protein and other debris that adheres to the surface of brain cells with Alzheimer's disease and denies those cells adequate nutrition to stay healthy and alive.

3. Neurofibrillary tangles = starvation

The third hallmark of Alzheimer's disease seen by the pathologist is changes on the inside of many neurons or brain cells.

When nutrients enter the cells, there are tiny tubules whose job it is to circulate the food throughout each cell.

Trainer: Show illustrations of healthy and diseased brain cells.

In this illustration you see an artist's conception of what these tubules look like inside a normal brain cell. They appear to be lying in an orderly fashion. Now here's an illustration of the artist's conception of a diseased brain cell. These tubules appear to be quite twisted and tangled.

Trainer: Show tangled, twisted straws or photograph of straws.

Let's imagine these straws as representing the feeding tubes of a diseased brain cell. Because they are twisted nutrients in the form of fluids cannot pass through. Think what would happen if your life literally depended on the intake of a nutritional supplement through a straw that was always twisted. Starvation would occur over time. The same outcome holds true for brain cells whose tubules have become twisted and tangled. They die of starvation.

Summary: Neurofibrillary tangles refers to what happens to the feeding tubules inside brain cells with Alzheimer's which eventually causes the starvation and death of those cells.

4. Neurochemical deficiency = low battery

The fourth hallmark of Alzheimer's disease describes a neuro-chemical deficiency that has been identified through extensive research.

Trainer: Show illustration of nerve cell communication.

To explain, here is another illustration that shows two neurons or brain cells. How they communicate with one another involves a unique communication system that relies on the availability of neurotransmitters to carry messages across the synapse or channel between them. One of the more important neurotransmitters released by brain cells is called acetylcholine. In Alzheimer's there appears to be a neurochemical deficiency or significant reduction in the amount of acetylcholine available for cellular communication, significantly reducing a person's ability to learn and remember as the disease progresses.

Trainer: Hold up two cell phones or show photograph of two phones.

Let's imagine that this cell phone has been communicating with a second phone without problems. Suddenly the quality of the communication begins to break down. Only bits of the message can be heard. Eventually there's static, then silence. The low battery of the cell phone no longer has enough electrical charge to enable a message to travel from it to another phone.

Summary: A deficiency of acetylcholine a neurotransmitter responsible for communicating information between brain cells, is evident in the brain with Alzheimer's disease and inhibits a person's ability to learn and remember new information.

Trainer: Review the four hallmarks of Alzheimer's disease. Please keep in mind that what occurs in the brain with Alzheimer's disease is far more complex than has been described in this training.



DEMENTIA CARE SERIES

Michigan Department of Community Health

THOUGHTS & SUGGESTIONS FOR CARING

Caring Sheet #1: The Healthy Brain and Cognition

By Shelly E. Weaverdyck, Ph.D.

Introduction

This caring sheet outlines the organization of the healthy brain and its cognitive functions.

Caring sheet #2 describes the brain changes in dementia and the impact these changes have on cognition. The resulting changes in cognition (i.e., the way in which a person thinks and processes information) lead to changes in behavior and the ability to perform tasks.

These two caring sheets (#1 and #2) are written as companion pieces with corresponding lists of intact and impaired cognitive functions. Other caring sheets discuss intervention strategies to address these cognitive changes.

Brain Organization

The brain is organized primarily into two halves called cerebral hemispheres. They are the **left hemisphere** and the **right hemisphere**. Each hemisphere is divided into four regions called lobes, three of which will be addressed here: the **frontal**, **temporal**, and **parietal lobes**. (The fourth lobe is called the occipital lobe and is crucial to vision. It allows the person to recognize or know what objects are, to recognize faces, and to see more than one object at a time, as well as other functions. Two additional major structures of the brain are not addressed in this caring sheet. They are the cerebellum and the brain stem. Other important structures are buried deep within the brain.) (See Figure 1.)

The **cortex** (from the Latin word for bark of a tree) is the surface of the brain as seen in Figure 1. It looks a little like noodles stuck together. This is where the most sophisticated cognition (i.e. higher intellectual thought processes) takes place. In general, the amount of surface area of the cortex correlates with the individual's quality of intellectual functioning.

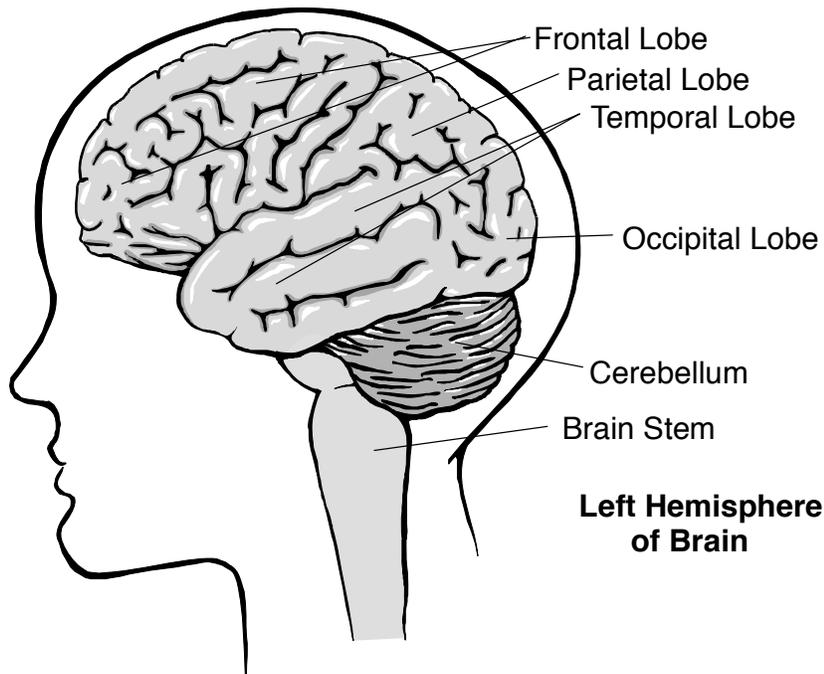


Figure 1: Schematic drawing of the brain, including the left cerebral hemisphere, cerebellum and brain stem. *Size and position of the brain with respect to the outline of the head is not to scale. The right side of the brain is essentially a mirror image of the left. The right cerebral hemisphere has the same four lobes.*

Cognitive Functions and Localization in the Brain

Some of the complex cognitive functions affected in dementia which are most noticeable to caregivers occur in the frontal, temporal, and parietal lobes of the left and right cerebral hemispheres. Those are the cognitive functions and brain structures addressed in this caring sheet.

Each lobe and hemisphere mediates or plays a major role in its own set of cognitive functions. Some of these cognitive functions are listed below.

There is a complex overlap and interaction of these functions among lobes and between hemispheres that varies from one person to the next. In addition, each lobe and hemisphere communicates with each other in complex ways, which also vary from one person to the next.



This outline of the general location of various cognitive functions in the cortex, within each lobe and hemisphere, therefore, is oversimplified and generalized.

The organization of functions also depends upon a person's structural dominance, as is partially evidenced by her/his hand dominance. Here the person described is assumed to be right handed.

(Left handed persons are usually similar to right handed persons. Some left handed persons, however may have functions controlled by both hemispheres or more rarely by the hemisphere opposite of what is listed here.)

Left Hemisphere (for most right handed people)

- controls sensory and motor functions of the right side of the body.
- helps the person recognize and use analytical or linear thinking, including language.
- When a person's left hemisphere is damaged the right side of the body tends to be weaker and altered in its ability to feel, notice, or recognize stimuli. The person may also have slurred speech or difficulty finding words she wants to use.

Right Hemisphere (for most right handed people)

- controls the sensory and motor functions of the left side of the body.
- helps the person recognize and use spatial aspects of information received from the environment.
- When the right hemisphere is damaged the left side of the body tends to be weaker and altered in its ability to feel, notice, or recognize stimuli. The person may also have difficulty locating objects in space or judging distances.



Frontal Lobe

The frontal lobe plays a major role in many cognitive functions, some of which are listed here. In general, the frontal lobe allows a person to:

- plan and organize
- make use of a pool of information or ideas, by sorting through and choosing from among them
- know when a task is done
- get started on a task
- recognize mistakes and correct them
- know how much time has passed
- recognize chronology of events in the past and put them in temporal perspective (e.g., I played as a child with my sister long before I cooked supper for my own children.)
- recognize and monitor her own thoughts and feelings
- discern triggers or causes of thoughts and feelings
- control impulsive responses to thoughts and feelings, by censoring, delaying, or pacing the responses
- adapt to new conditions
- switch from one idea or action to another
- imagine something not visible or tangible (i.e., abstract)
- recognize or know the order of task steps or items
- think about or do more than one thing at a time

Temporal Lobe

The temporal lobe, among other functions, allows a person to:

- comprehend language (in the left hemisphere)
- express language (in the left hemisphere)
- remember very recent events or information (in cooperation with the hippocampus, a structure tucked behind the temporal lobe) (e.g., it prevents a person from repeating the same story in a single conversation or forgetting that a visitor had just been there)



Parietal Lobe

The parietal lobe, among other functions, allows a person to:

- recognize spatial information (in the right hemisphere) (e.g., it allows a person to recognize where people or objects in a room are in relation to each other and to the person's own body)
- organize spatial information (in the right hemisphere) (e.g., it allows a person to draw and to set the table in a spatially correct way)
- integrate and organize sensory information (particularly visual)
- write and to perform arithmetic (in the left hemisphere)
- recognize her own body and its left/right orientation

Other areas of the brain play a role in all of these functions, and many cognitive functions are not listed here. These are some of the most complex cognitive functions frequently impaired in brain damage or in dementia. Impairment of these functions can create or contribute to some of the behavioral changes evident to caregivers.

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Editor and content coordinator: Shelly Weaverdyck, Ph.D. at EMU-HW, Email: sweaverd@umich.edu

To order a copy of this caring sheet and receive a complete listing of additional caring sheets available, contact Matt Beha at the Mental Health and Aging Project. Address: Lansing Community College, 3500-MHAP, P.O. Box 40010, Lansing, MI 48901-7210. Phone: 517/483-1529 Email: beham@lcc.edu

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DEMENTIA CARE SERIES

Michigan Department of Community Health

THOUGHTS & SUGGESTIONS FOR CARING

Caring Sheet #2: Brain Changes and the Effects on Cognition

By Shelly E. Weaverdyck, Ph.D.

Introduction

This caring sheet describes the brain changes in dementia and the impact these changes have on cognition. It is the change in cognition (i.e., the way in which a person thinks and processes information) that leads to changes in behavior and the ability to perform tasks.

Caring sheet #1 outlines the organization of the healthy brain and cognitive functions.

These two caring sheets (#1 and #2) are written as companion pieces with corresponding lists of intact and impaired cognitive functions. Other caring sheets address intervention strategies to address these cognitive changes.

Dementia

Dementia is a decline in a person's cognition. This decline occurs because of changes in the brain.

Some brain changes in older adults can be **temporary** and **treatable** (e.g., delirium) if they are caused by treatable disorders such as:

- urinary tract infection
- vitamin deficiency
- constipation
- flu
- depression
- reactions to medications



Other brain changes are **irreversible** and **progressive** (i.e., increasingly severe) if they are caused by disorders such as:

- Alzheimer's Disease
- Multi-infarct Dementia or Vascular Dementia
- Creutzfeldt-Jakob Disease
- Dementia with Lewy Bodies

This caring sheet describes the irreversible, progressive brain changes and the resulting cognitive impairment.

Sometimes both temporary and irreversible changes occur simultaneously. When the disorder causing the temporary changes is treated immediately, the person usually returns to the level of cognitive functioning caused by the irreversible brain changes.

Alzheimer's Disease is the most common cause of irreversible brain changes & dementia in persons over the age of 65 years. It affects the person's:

- behavior
- personality
- cognitive skills (such as reasoning, judgment, and memory).

Though these changes in behavior and cognition result from brain damage, they are often mistakenly viewed as intentional or manipulative.

Alzheimer's Disease

In Alzheimer's Disease there are four hallmark pathological changes to the brain: atrophy, neuritic plaques, neurofibrillary tangles, and neurochemical changes.

- **Atrophy** is the reduction in size of a structure. Atrophy due to death of nerve cells in Alzheimer's Disease causes much of the confusion and cognitive impairment. Atrophy occurs with normal aging, but is especially pronounced and is pathological in Alzheimer's Disease. The atrophy is visible on a CAT scan and at autopsy.



- **Neuritic plaques** are little patches or collections of debris in the brain. They are located outside of nerve cells. A protein called amyloid is at the core of the plaques. The number of neuritic plaques correlates with a person's performance on cognitive tests (such as Intelligence or IQ tests).
- **Neurofibrillary tangles** are inside nerve cells, particularly in the axons of nerve cells. Axons are the protrusions from the nerve cell body, which carry information from one nerve cell to the next. Tiny neurofibrils (filaments or tubules) transport cell nutrients within the nerve cell. The neurofibrils become tangled in a very characteristic way (double helical) and therefore disrupt the cell maintenance processes, probably contributing to the cell's death. The number of neurofibrillary tangles also correlates with a person's performance on various cognitive tests.
- **Neurochemical** changes also occur in Alzheimer's Disease. There is a reduction in some of the neurotransmitters. Neurotransmitters (the chemical messengers) are neurochemicals which are transferred from one nerve cell to another as a method of communication with that nerve cell. This intercellular communication is essential to the brain's maintenance and functioning. There are many different kinds of neurotransmitters. One, which is particularly reduced in amount in Alzheimer's Disease, is called acetylcholine.

Multi-Infarct Dementia (MID)

In Multi-Infarct Dementia (MID), the brain has many tiny strokes on the cortex or surface of the brain. Spots of softened dead tissue (lesions) occur throughout the cortex. These lesions can be seen on a CAT scan, but not always. A CAT scan can rule out the possibility of a major stroke as a source of the cognitive impairment.



The Brain

The occurrence of these pathological changes in specific parts of the brain directly correlate with changes in specific cognitive functions.

The structure of the brain and organization of its cognitive functions was described in Caring Sheet #1.

The focus of that sheet (and of this sheet) is the **cortex**, the bark or noodle-like surface of the brain where the most sophisticated intellectual thought processes take place. In general, the amount of surface area of the cortex correlates with the individual's quality of intellectual functioning.

Caring sheet #1 described the two halves of the brain (the **left and right hemispheres**) and three of the four lobes which compose each cerebral hemisphere (the **frontal, temporal and parietal lobes**). (See Figure 1.)

Caring sheet #1 noted that each lobe and hemisphere has its own set of cognitive functions in which it plays a major role. It listed some of those functions.

The damage in the frontal, temporal, and parietal lobes in the cortex are particularly related to the impairment in dementia of the cognitive functions listed there. (Other important impairments result from damage to a fourth lobe, the occipital lobe including an impaired ability to recognize objects and faces, and to see more than one object at a time.)

Individualized Brain Organization

It is important to note that the lobes overlap and interact in the control of cognitive functions, and that they communicate with each other in ways somewhat idiosyncratic to each individual person.

This listing of specific cognitive functions as the province of each lobe, therefore, is an oversimplification and generalization, though there is clearly a strong correlation between damage to specific lobes and corresponding impairment in specific cognitive functions.

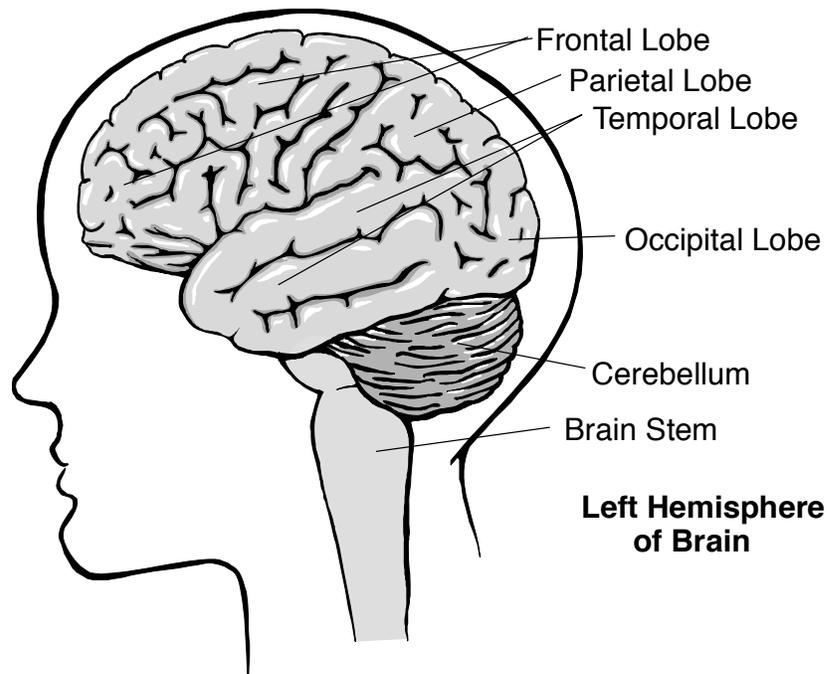


Figure 1: Schematic drawing of the brain, including the left cerebral hemisphere, cerebellum and brain stem. *Size and position of the brain with respect to the outline of the head is not to scale. The right side of the brain is essentially a mirror image of the left. The right cerebral hemisphere has the same four lobes.*

Cognitive functions are organized in the brain according to a person's structural dominance, as is usually evidenced by hand dominance. Here, we are assuming the functions described are of a typical right handed person. (This would pertain to most, but not all left handed persons as well.)

Brain Damage in Dementia

In dementia, the pathological changes to the brain described above (the atrophy, neuritic plaques, neurofibrillary tangles and neurochemical



changes) occur in both hemispheres and in all three of the lobes discussed here. (They occur in other parts of the brain not discussed here, as well.)

The pathological changes do not occur all at once, but gradually spread across the brain. As each lobe is affected by the pathological changes, there is also a gradual increase in severity or amount of pathological change within that lobe, even as it is beginning to spread to other lobes. As a result, the change in cognition or dementia is usually gradual and progressive. This is in contrast to most major strokes, where one hemisphere is primarily affected and the brain damage occurs suddenly and all at once.

The progression of the pathology across the brain, and the order in which the lobes are affected, depends somewhat upon the type of dementia and the type of disorder causing the dementia.

The spread and increase in severity of the pathological changes across the brain, causes the dementia to progress through stages commonly seen by caregivers.

Brain Damage & Cognition in General

When one lobe or area of the brain is damaged, the functioning of the whole brain is affected, but the cognitive functions in which the damaged area or lobe play a major role are particularly impaired.

As a person ages from birth to old age, each lobe and hemisphere becomes increasingly specialized in the cognitive functions it performs.

When part of the brain is damaged, the rest of the brain tries to take over the functions the damaged part had been mediating. The older the brain is, the more specialized each lobe and hemisphere is, and the more difficult it is for other parts of the brain to recover the affected functions.

In dementing disorders such as Alzheimer's Disease, while repair mechanisms may be at work, the pathological changes appear to spread more quickly than the ability of the other parts of the brain to recover the lost functions. In less progressive disorders, such as major strokes, even brains that are quite advanced in age, seem to recover functions more easily.



Cognitive Changes in Dementia Resulting from The Brain Changes

In both Alzheimer's Disease and MID, evidence of the pathology (i.e., the signs and symptoms of cognitive impairment) may become apparent as each lobe becomes significantly affected by the pathology.

The amount of pathology required in each lobe to create the cognitive and behavioral changes noticeable to a caregiver, depends upon the individual brain, person, and circumstances.

Many of the changes seen in behavior and in the ability to perform daily tasks are directly caused by the cognitive changes that result from the pathological damage to the frontal, temporal, and parietal lobes.

As the pathology spreads to and multiplies in each lobe the effects are very specific to the cognitive functions mediated by that lobe. Thus, as each lobe becomes damaged by the pathology, a new set of cognitive functions becomes impaired and becomes increasingly impaired as the disease progresses.

To the extent the spread of pathology and its rate of increase in severity in each lobe is similar among individuals, the individuals will pass through similar stages during the course of the dementing disorder, though with some individual variation.

Progression of Cognitive Impairment

Cognitive abilities are always gradually changing because the pathology is always gradually spreading and increasing in severity.

Not only is the general change in cognition gradual, but each cognitive function, itself also becomes impaired gradually.

- First there are isolated instances of symptoms (e.g., the person forgets how to get home from the store one day).
- Then instances of this impairment become more frequent (e.g., the frequency with which the person gets lost coming home from the store increases).
- This cognitive impairment continues to increase in frequency and severity (e.g., the person frequently gets lost and increasingly has



difficulty recognizing her disorientation and knowing how to get help).

- The frequency and severity continues to increase as another cognitive impairment begins to appear in isolated instances and gradually increases in frequency and severity.
- Each cognitive function continues to increase in severity and frequency; it does not stay at the same level as other cognitive functions change.

Cognitive Impairment & Parts of the Brain

The impaired cognitive functions listed here correspond to the intact cognitive functions listed in Caring Sheet #1.

Left Hemisphere (for most right handed people)

When a person's left hemisphere is damaged:

- the right side of the body tends to be weaker or unable to move.
- the right side of the body may be altered in its ability to feel, notice, or recognize stimuli.
- the person may also have slurred speech or difficulty finding the words she wants to use.

Right Hemisphere (for most right handed people)

When the right hemisphere is damaged:

- the left side of the body tends to be weaker or unable to move.
- the left side of the body may be altered in its ability to feel, notice, or recognize stimuli.
- the person may have difficulty locating objects in space or judging distances. An environment with many objects or much movement can be very upsetting or fatiguing for this person.

Frontal Lobe Impairment

As the frontal lobe becomes affected cognitive symptoms become evident. The person may have difficulty:



- problem solving and planning a task.
- thinking of ideas for conversation, of activities to relieve boredom, or of possible explanations for an event (e.g., the only explanation for odd tasting water is that you're poisoning me).
- recognizing when she is done with a task such as eating a meal.
- initiating a task (e.g., a person may sit in front of a lunch plate and start eating only when another person initiates the process for her; she may appear lethargic or uninterested).
- recognizing or correcting mistakes in social protocol (e.g., will pinch a caregiver's breast, and laugh about it, but not recognize the extent to which the action was inappropriate; or might take a blouse off because she's hot even though she is in the living room).
- knowing how much time has passed (e.g., may sit down to eat and then get up and walk away after a few bites; or may ask when dinner is twenty times in three minutes, because she thought perhaps a half hour had passed since she had last asked).
- understanding the sequence of events in past or present time (e.g., understanding why the fact that she is 90 years old and her children are in their 50s and 60s means that she does not need to go home to feed her children).
- recognizing the depth of his own emotion or even that he is angry, sad, or upset; as well as difficulty in recognizing what he knows (e.g., he may know which chair he always sits in for lunch, but may say he doesn't know, even as he walks to the chair on his own and sits down.) The ability to consciously monitor and "watch" oneself is impaired.
- analyzing why she is feeling an emotion (e.g., she may say she wants to go home, but in fact she is anxious and cannot think of any other reason for her anxiety).
- thinking twice before acting or saying what comes to her mind (e.g., she may swear or say "She's fat" about someone walking by).
- adapting to new situations or conditions. She may feel anxious or be unable to do a task in unfamiliar surroundings or with unfamiliar task objects (e.g., she may have difficulty brushing her teeth with pump



toothpaste instead of tube toothpaste, or changing morning routines and bath times from past habits). She is most relaxed and can perform tasks most successfully when the caregiver is consistent and conditions are as they were throughout most of her adult life.

- changing from one thought or activity to another. (e.g., when he is privately reminiscing about a game of baseball from the remote past, it is difficult for him to quickly attend and recognize someone walking by saying “hi” or asking him to take some medication.)
- creating a picture in her mind of an object in order to understand or recall what someone is saying (e.g., choosing between two food options that are not in front of her; or recognizing that a clear glass has water in it when the water seems invisible).
- conceptualizing the order of task steps or items (e.g., the order of clothes to put on).
- thinking about or doing more than one thing at a time (e.g., feeling embarrassed about a behavior and changing the behavior).

Temporal Lobe Impairment

As the temporal lobe becomes affected other cognitive symptoms become evident. The person may have difficulty:

- understanding the words another person is using.
- producing the words he wants to use.
- remembering what she told someone two minutes ago.

Parietal Lobe Impairment

As the parietal lobe becomes affected additional cognitive symptoms become evident. The person may have difficulty:

- recognizing where objects or people are in the environment, particularly when they are moving.



- performing tasks which require manipulation of objects or of his own body, particularly in relation to other objects (e.g., dressing, setting the table or navigating large spaces).
- performing simple arithmetic calculations.
- responding to a request to walk or to move a part of her body.

As was said above, the changes in cognition resulting from pathology of each of these lobes in the brain, occur as the lobe responsible for each function becomes damaged. The particular order and severity of each function varies with each individual person with dementia.

Another caring sheet suggests interventions that address these cognitive changes.

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Editor and content coordinator: Shelly Weaverdyck, Ph.D. at EMU-HW, Email: sweaverd@umich.edu

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DEMENTIA CARE SERIES

Michigan Department of Community Health

THOUGHTS & SUGGESTIONS FOR CARING

Caring Sheet #19: Intervention Suggestions for Frontal Lobe Impairment

By Shelly E. Weaverdyck, Ph.D.

Introduction

This caring sheet lists intervention strategies to try when communicating with someone who has frontal lobe damage. Caring sheets #1 and #2 describe the healthy brain and the impairments resulting from brain damage to various parts (lobes) of the brain, including those of the frontal lobe. Frontal lobe dysfunction is common in all types of dementia.

Frontal Lobe Impairment

People with damage to the frontal lobe of the brain frequently experience changes cognitively, emotionally, and behaviorally. Some changes are briefly outlined here. There is more detail in caring sheets #1 and #2.

Cognitive

People with brain damage to the frontal lobe at times:

1. Cannot rationalize. They often cannot understand and make use of a caregiver's explanation, even though they may talk as though they do.
2. Can only do one thing at a time.
3. Can get stuck on one idea or task and find it hard to shift (one-track mind).
4. May not recognize they made a mistake.
5. Cannot monitor or observe themselves. They often have difficulty correcting their behavior.
6. Cannot sustain concentration or performance of a task for very long.



7. Cannot easily screen out irrelevant stimuli from the environment. They tend to respond to many stimuli, particularly the most powerful stimulus at any given time.
8. Cannot understand new or confusing changes to their environment or experience. They cannot adapt easily. They depend upon a consistent and obvious structure to their day and to the space around them.

Emotional

People with brain damage to the frontal lobe at times:

1. Cannot express their anger appropriately. They may sometimes appear more angry than they feel. For example, a little irritation can sometimes produce profuse swearing. It just sounds like they're very angry.
2. May look more angry than they are because of their slightly monotonic speech and rigid set face.
3. May focus their anger about their lack of control and their disabilities on other people. This is sometimes alleviated when they are in situations where they do feel they have some control.

Behavioral

People with brain damage to the frontal lobe at times:

1. Seek out other people or collect things because they don't want to be alone or they want to be busy. They are often panicking inside.
2. Are impulsive in what they do and say. They may not think twice before speaking, or they may do whatever comes to mind. They are often unpredictable.

Communication Interventions

1. Get their attention before speaking or communicating nonverbally.
2. Be close to them when speaking (e.g., right in front of them). How close is appropriate varies with individuals. Don't call or talk from across the room.
3. Present only one idea at a time.



DEMENTIA CARE SERIES

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Intervention: Frontal Lobe Impairment

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4. Use short phrases or words. Two to three words are better than long sentences. Especially when they are anxious or panicking inside. (Panic may not be obvious in behavior or expression. Sometimes people act angry when they are really frightened.) They cannot process more than a couple of words at a time, even if they are using many words themselves.
5. Be kind, respectful, and gracious, especially when giving a clear short request. Requests or instructions should be clear, but not terse or demanding. Avoid sounding bossy or like a parent; avoid stating a request as though it were a command. The goal is to sound soothing, neutral, and nonthreatening.
6. Be patient and gentle, even when firm. Avoid scolding a person. Sometimes scolding seems to work because when we scold we tend to also be very clear and to use few and short words or phrases. But it is usually the clarity that is most effective, rather than the scolding.
7. Give them time to process what you said and to respond.
8. Try hard to learn as much as possible about each person's past: their interests, hobbies, goals in life, and personality. Use such information in conversation and when distracting the person.
9. Keep them busy. Sometimes hoarding, pacing, or repetitive questioning may be an attempt to do something when they don't know what else to do with their anxiety and frustration.
10. Because they cannot screen out stimuli from the environment easily, they may often seek the quiet of their room or the outdoors. Frequently, however, they will not stay there long, because they may also feel uncomfortable being alone. Calm and quiet areas within sight of caregivers are helpful.
11. Have only one caregiver interact with a person at a time.
12. Try to create consistency and simplicity. Keep the daily routines and tasks as consistent as possible. Try to have the same people interact with the person every day. Keep the number of people interacting with them as small as possible. Avoid changes in the environment. (For example,



- avoid rearranging furniture or rearranging the position of food items at meals.)
13. Present each step of a task one at a time, so the whole task doesn't feel so overwhelming.
 14. Reduce the number of food utensils and food items, so they have fewer objects to deal with.
 15. Avoid talking or moving quickly.
 16. Avoid drawing attention to the person's behavior. They may not be able to monitor their own behavior and feel their feelings at the same time.
 17. Avoid focusing on or trying to quickly change their emotions or behavior (unless it's dangerous). They will likely subside soon if you let the emotions or behavior run their course.
 18. Avoid saying "no" to their requests. That would require them to shift out of the idea they have at that time. Try offering a different idea or letting the request fade away by repeating the request back to them, talking more about it, or by suggesting you and they do something else first.
 19. Let the person know you understand they are upset and that they are okay.
 20. Help them feel it's you and them against the problem, not you against them. For example, if they have left the room and you want them to turn around, go their way with them first. Soon they may start moving to your speed and direction as you gradually guide them back to the room.
 21. Don't laugh or talk about them in front of them. Take them seriously.
 22. Avoid correcting or saying "that's not nice". It might make the person more upset.
 23. When you need to quickly stop them from doing something, place yourself between them and their target (if they are going to hit someone), and deflect their hits with the open palm of your hand. Avoid touching them as though you are attempting to restrain them. Avoid using words (or many words) until they have calmed down. Try to appear calm, reassuring, and comforting, without being condescending.



24. Individualize all your responses and interventions by recognizing the unique needs and desires of each person you interact with. Each person will respond uniquely to frontal lobe impairment.
25. Try to identify and to remind yourself regularly of what it is you love about this person. The frustration of caring for the person can sometimes make us forget what is lovable about her or him.

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The author, Shelly Weaverdyck is Director of the EMU-HW Alzheimer's Research Program.

Editor and content coordinator: Shelly Weaverdyck, Ph.D. at EMU-HW, Email: sweaverd@umich.edu

To order a copy of this caring sheet and receive a complete listing of additional caring sheets available, contact Matt Beha at the Mental Health and Aging Project. Address: Lansing Community College, 3500-MHAP, P.O. Box 40010, Lansing, MI 48901-7210. Phone: 517/483-1529 Email: beham@lcc.edu

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SLIPSHEET

Session 3: Respecting the Humanity of the Person with Dementia

Anne Robinson and Beth Spencer

Interactive Training Strategies

- Dorothy Luther sequence, including video clips, discussion questions, photographs and life story.
- Exercises to identify core qualities.
- Care-planning exercises.
- Imagine exercises.
- Video clips of Irene Schwartz and Susie Thomas with discussion questions.
- Powerpoint slides.

SESSION 3

SUGGESTIONS FOR TRAINER

Respecting the Humanity of the Person with Dementia

The goals of this session are:

- To sensitize staff to the experience of what it means to have dementia.
- To assist staff in seeing the individuals they care for as human beings who have feelings, emotions and needs and not just as "patients" diagnosed with a disease.
- To teach staff that each of the residents in their program has a unique life story that needs to be understood and respected when they are assisting with care.
- To teach staff that people with dementia have remaining abilities and strengths and that our primary goal as caregiver is to help each person continue to live as normally and meaningfully as possible.

This session is really the core of person-centered training. Its focus is to help staff begin to imagine what it feels like to be a person with dementia. It is only when people can begin to do this that they can begin to provide person-centered care.

A number of interactive training suggestions are included in this session aimed, at helping staff see the person behind the disease. **In reality, we begin our training with some of these strategies and continue to use them throughout** whatever training we do. While we are training staff about the changes in the brain, the forms of dementia, about ADLs, we continually bring them back to thinking about who the person with dementia is and how we can make life as meaningful as possible for him or her.

Using the *Outline*

There are many ways to use the material in this session. We use experiential exercises, videos, and memoirs written by individuals in the early stages of dementia. These are all different ways of helping staff begin to imagine and empathize with the experience of living with dementia. We always incorporate some of these experiential activities into multiple training sessions, in order to keep reinforcing the importance of thinking about each resident's experience and feelings. **It is important to use a variety of techniques to help staff caregivers understand what it feels like to be a person with dementia, as different strategies will work with different staff.**

Recognizing a Person's Essence or Core Qualities

What do we mean by person-centered care? To provide care to people with dementia that is truly individualized or person-centered, we have to have some understanding

- of what has made each person unique;
- of what his or her personality has been;
- of what the core qualities are that define this particular person; This is not an easy thing to know about someone with dementia, whose personality may have changed and whose core qualities may be somewhat submerged.
- of how staff take all of this information into consideration and use it as they assist the person with care.

The essence of human beings consists of those core qualities deep down inside that define who we are – our sense of values, what's important to us, those personal qualities we hope will be recognized and remembered by others. This is not meant to imply that our memory is any less a part of who we are. On the contrary, our memory allows us to recall images of the past, of persons and experiences that help define who we are. Our memory

of recently learned information allows us to plan, to move forward, to feel safe.

However, we are so much more than memory. When asked, people indicate that they want to be remembered for the qualities that make them who they are, e.g., honest, cooperative, ambitious, friendly, generous, trustworthy, intelligent, talented, purposeful, passionate...not for their memory skills.

We believe that much of the essence of a person with dementia remains intact throughout the disease process and can be accessed and often engaged when using a person-centered approach. **Recognizing the essence or core values of persons with dementia reawakens their awareness of self and others and paves the way for developing meaningful relationships.**

When we build this relationship and use the information during person-centered care, it often makes the task go more easily. It becomes a win-win situation for everyone.

We have developed a series of tapes and exercises to help staff begin to think about this concept of core values:

- Three videotape clips of Dorothy Luther on the Training Tape (DVD).
- A brief life story of Mrs. Luther, written by her daughter.
- Discussion questions to help staff think through how to use this information in providing care to Mrs. Luther.
- A core qualities exercise which asks staff to think about those attributes that make them who they are.

Who is Dorothy Luther? As you show the first video clip, don't give staff any history at this point, although you might want to put up one of the photographs of Mrs. Luther from the CD. What you want them to do is begin to try and identify characteristics or qualities that define this particular woman. Tell them they will be watching a resident named Dorothy Luther in an assisted living facility, Huron Woods. As they watch,

you want them to think: Who is Dorothy Luther?

In the *Outline* there is a description of each video vignette with accompanying discussion questions. We have included the first description here, so that you can get a sense of how to use these vignettes. The rest are in the *Outline*.

Video Vignette #1 of Dorothy Luther

In this vignette, Mrs. Luther is folding napkins for an afternoon tea that is being held at Huron Woods for some women from a local church. Although it is subtle, one can begin to see some of the characteristics that make Mrs. Luther who she is. In the *Outline*, we have identified some of the core values that staff might be able to identify from this videotape clip.

- What did you learn about Mrs. Luther from this videotape clip? What would you say are her the qualities or characteristics that make her who she is?

Note to trainer: Typically there is a pause – this approach is very different from what staff are used to. Allow some silence as they think about these questions. Write their ideas and thoughts on the board or newsprint. It is okay if they only identify two or three qualities. In the *Outline*, we have provided some possible answers to these questions for each of the three Dorothy Luther video clips. After you have made a list together, look at the other two clips. After each, ask the same questions and add to your list of core qualities and characteristics of Dorothy Luther.

Dorothy Luther Story. On the CD is a handout entitled Sample Family Story: Who was Ms. Dorothy Luther?, which is a description of Dorothy Luther written by her daughter, Anne, who then listed what she sees as Mrs. Luther's core qualities. Following the video clips, pass this story out or read it aloud and ask staff what other core qualities they can identify from the

story. Although not all families will be able to provide this type of in-depth information about their relatives, when they can, it is very useful. In the Outline and on a powerpoint slide, we have included the list of core values that Anne compiled after writing the life story. When you put the overhead up with Anne's list of Dorothy's core qualities, discuss with staff how their own list compares. Be sure to give them positive feedback on whatever qualities and abilities they were able to identify.

There are also photos of Mrs. Luther at different points in her life on the CD. As you or staff members read the life story aloud, put the photos up on the overhead projector, so that staff can gain even more of a sense of Dorothy Luther and her life.

Using Core Qualities to Plan Care

After identifying a person's core qualities, the key concept is to think about how to use this information to improve the person's daily care. A little later in this section we have offered ideas for gathering and using information about the people we work with.

It is important to practice with staff how to use the core qualities and abilities identified for Dorothy Luther. Her daughter, Anne, has identified a series of questions and suggested answers to help staff think through how to use this information in providing care to Mrs. Luther. The discussion questions are listed below. In the Outline some suggested answers are also included. Undoubtedly staff will come up with others that we have not thought of.

- What day-to-day activities might Mrs. Luther especially enjoy?
- How might we approach and interact with Mrs. Luther in ways that would make her feel at home?
- How can we help her maintain her considerable energy?

- How might we build on Mrs. Luther's enjoyment of helping others?

There is a brief discussion to be had with staff at this point about care plans and building this kind of information into them. **Too often care plans are full of jargon, are abstract, and are not useful to staff** in knowing how to provide daily care that incorporates key information about the person they are caring for.

- How could we build what we know about Mrs. Luther into her Care plan? What approaches to ADLs might we take with Mrs. Luther, recognizing her independent spirit and her belief that she knows the best way to do things?
- Mrs. Luther's adult life was devoted to her role as a minister's wife, Sunday school teacher, and mother and she loved church music. How can we use this information in Mrs. Luther's Care plan to help when she is agitated?

Exercise: Core Qualities of Staff – Who are you?

After a discussion about Mrs. Luther and the qualities that made her unique, it is time to help staff try to identify their own core qualities. There are several ways of doing this exercise. Whichever method you use, it is an important piece of helping staff think about what makes each person unique and why it is critical to try to identify these characteristics in the people we work with.

Method 1. Ask staff to take a moment and think about what makes each of them themselves. Have them write down three things they would like to be remembered for after their death. Ask them to share some of the qualities they have identified in themselves and list some their answers on the board or newsprint.

A list of core qualities might include: Honest, compassionate, cooperative, caring, giving, loving, kind, friendly, generous, fair, trustworthy, humorous, intelligent; passion

for travel, politics, music, theater, art, good food, beautiful things, family; talent such as woodcarving, cooking, sewing, singing, dancing, storytelling; hobby such as model trains, doll collecting, vintage cars, jewelry, fishing, gardening, birding, hiking, writing, volunteering.

Method 2. When asked to describe their own core qualities, some people may feel too self-conscious and too exposed. This method will probably make it easier for them.

Ask staff to write their first names vertically (top to bottom) on a piece of paper. Using each letter in their name as a guide, instruct them to write down some of their core qualities. Ask each person to share their list with everyone.

In the *Outline*, there are some examples from staff members who have done this before. Share one or two to help your staff get started. Some suggestions for concluding remarks for the Core Qualities exercises are included in the Outline.

Gathering and Using Key Information about Residents

It is important at some point to have a discussion about how information about residents is, can, and should be shared with staff. You may want to look at the handout together, **Getting to Know the Person with Dementia**, and discuss ways of gathering this kind of information in your setting.

Often when staff in residential programs meet the person with dementia for the first time, the person already has significant impairments. Staff come into the person's life at a time when the individual is no longer able to share many of the details about what life has been like. While biographical information is routinely gathered from the family at the time of admission, it tends to be factual and cursory. Staff get a brief overview of the person's life, but there are a lot of missing

pieces – particularly the core qualities of that person, or the essence of who that person has been.

One of the challenges for programs is finding ways to get key information to the direct care staff who need it most. Staff need to understand the importance of and be held responsible for knowing that key information.

Some suggestions of ways to gather and use information:

- Staff input. Review with your staff the information you currently have on residents. Get their suggestions for information they would like to have, questions they would like families or residents to be asked, and ways of making that information easily accessible to staff.
- Family questionnaires. We have included questions both in the handout mentioned above and in Session 5, which has very specific questions on daily routines and habits. Again, it is critical to think about how all this information can be made useable and accessible to staff. Be aware that many families cannot or will not take the time to fill out extensive questionnaires.
- Family stories. Another way of getting to core qualities is to ask family members who are able to write down stories or information about the unique characteristics of their relative. We have included a sample of Dorothy Luther's story as a handout with photos at the end of this session. This sample could be shared with families to give them a model to follow.
- Photographs. Photo collages or albums of the person's life with short descriptions are another way for families to provide staff with important background information about residents. There are advantages

to collages since they can be out where everyone sees them regularly; sometimes photo albums get put away out of sight. Encourage families to select photos that show the person in places and with people whom they may remember or who have been important to them. Ask them to label photos in large print so that residents as well as staff can read them.

- Binders. Some residential care facilities have binders that have a sheet of paper for each resident with key information on it that staff should know. The binders are kept in an accessible place and are required reading for staff.
- Resident biographies. In some settings there are biographies posted by resident rooms. Ideally they have been carefully crafted by families and/or staff to include core qualities and key things to know about each person.

In *The Best Friends Approach to Alzheimer's Care* (Bell and Troxel, 1997), there is an excellent chapter on how to put together a person's life story. *Alzheimer's Disease: Activity-Focused Care, Second Edition* (Hellen, 1998) also has a section with specific questions to consider when putting together a life story. *Rethinking Alzheimer's Care* (Fazio et al., 1999) has a chapter entitled "Rediscovering the Soul," which explores similar questions. (See *Reference List*.)

Imagine Exercises

We often ask staff to think about the feelings they might experience if they were diagnosed with Alzheimer's disease. An Imagine exercise is one way of beginning to help them walk for a moment in the shoes of someone with dementia.

What would it be like to have problems with your memory? To know that eventually things will get worse? To know that you will no longer be able to take care of yourself?

Imagining how you might respond in this kind of a situation and the impact this condition

might have on your life can be a powerful way of helping staff to develop empathy.

Jitka Zgola (1999) created an *Imagine* exercise that is included in the *Outline*; another one is on the CD for your use. These are descriptions of feelings and reactions to situations, written from the perspective of the person with dementia. Some staff are able to really imagine themselves in the scene; for others it is much more difficult

We have found the best way to use an *Imagine* exercise is to:

- Choose one ahead of time to use in your training.
- Ask staff to close their eyes, relax, and get comfortable in their seats.
- Give them a few moments to get focused and ask them to concentrate as you read to them.
- Read the exercise aloud to them in a slow, measured voice, with feeling.
- Debrief with specific discussion questions:
How do you feel with these things happening to you? List feelings.
What do you need from staff to help you cope with these feelings?
 - emotional needs
 - physical needs
 - other (e.g., psychosocial, spiritual, cognitive).
- Be sure you write everyone's answers on a blackboard or newsprint.
- Do not rush this process. If you allow an occasional silence, staff will often come up with even more comments or insights.

Sometimes questions about the level of awareness that people with dementia have throughout the course of the condition come up. Is the person aware of what is happening to them? We still know so little about the experience of dementia. Yet, we strongly believe that the voice of the person with dementia is still there, trapped inside a

mind that is unraveling because of profound changes in the brain. While the person may no longer be able to communicate verbally, there are moments when there may be recognition that something is dreadfully wrong. It is important to take the time to talk about this with staff.

Training Tape Vignettes

There are several video clips on the **Training Tape (DVD)**, which can be used to talk about the importance of respecting the humanity of the person, and understanding the background of the person as well.

We have included background information here for you to use with staff as you use these other vignettes, which is summarized on the powerpoint slides on the CD. The brief descriptions of the vignettes and discussion questions are in the *Outline*.

Irene Schwartz Training Tapes - Background

Mrs. Schwartz was born in Hungary in 1906. She was one of three children. Her father died when she was two years old. Shortly thereafter, her grandmother and mother emigrated to the U.S. and settled in Chicago. Mrs. Schwartz graduated from high school and supported herself as a waitress while going to Northwestern University where she completed a degree in biology. She taught school for several years during the Depression.

Mrs. Schwartz was married in 1939 to Samuel who was studying medicine. Upon graduation he accepted a position with the Bureau of Indian Affairs. They spent several years living in Lapwai, Idaho and Redmond, Oregon – two very remote areas. Samuel served as a physician to Native American families living on the reservations. They moved back to the Chicago area in the mid-1940's where Mrs. Schwartz gave birth to her daughter, who was an only child. She also taught Social Studies and English to 7th and 8th graders. She loved to teach until she retired in the 1960's.

Mrs. Schwartz's social life revolved around her immediate and extended family. She enjoyed playing "hostess" at weekly family gatherings. She loved to cook, especially fancy desserts such as ice cream cakes and blueberry strudel. She also enjoyed reading, particularly Jewish topics and fiction books. She loved current events, concerts that involved dancing and she played scrabble and bridge.

In the 1960's Mrs. Schwartz and her husband traveled throughout Europe, Eastern Europe and Israel. In the 1980's her husband developed heart problems and Parkinson's disease and died in 1986. It was a devastating loss for Mrs. Schwartz. Two years later, she moved into a retirement community in Chicago and began experiencing memory problems. In 1993 an accountant discovered discrepancies in Mrs. Schwartz's finances. Her daughter subsequently encouraged Mrs. Schwartz to move to Michigan so that she could be closer to her family. In 1993, Mrs. Schwartz moved into Huron Woods, an assisted living facility.

Mrs. Schwartz was a very independent woman who had definite opinions about how things should go. She had little tolerance for playfulness and was often critical of activities that appeared child-like or frivolous. Finding meaningful things for Mrs. Schwartz to do was challenging for staff.

A weekly discussion group was formed and Mrs. Schwartz was invited to join. Initially it was challenging to get her to come to the group but with the help of freshly baked muffins and cookies, she became a loyal member. Mrs. Schwartz particularly enjoyed interacting with a retired professor in the group who was also of European Jewish descent. Sigmund and Mrs. Schwartz became good friends and she looked out for him.

Video Vignette of Susie Thomas - Background

Susie Thomas was born in Georgia in

1920, and raised in Philadelphia by a foster family. She lived there until her health declined; in 1995 she moved to a long term care facility in Michigan. Miss Thomas never married, always living alone. She tells wonderful stories of her very independent life in Philadelphia. She was proud of her position in the Baptist Church where she was an usher, which was a very prominent and respected position. She took her responsibilities seriously and was known to frequently provide the neighborhood children with home-baked treats as they stopped by after school. Miss Thomas was extremely social and involved in church activities. She loved to cook and bake, read the Bible, sing hymns, take walks outside with her cat and dog, and play the piano.

Miss Thomas was diagnosed with congestive heart failure, diabetes, edema, arthritis, cataracts, and depression. When this video was made, she was considered to be in the middle stages of vascular dementia (small strokes). She has a short-term memory problem and does not remember taking medication or the need for insulin. Miss Thomas does not understand or accept her need to receive care. She has a history of falls and requires supervision and cueing with toileting and bathing. She has a limited range of leg and arm motion on both sides of her body, experiences moderate pain, and occasional incontinence.

Miss Thomas communicates well verbally, despite difficulties with short-term memory. Her change from independence to needing care happened suddenly when she became very ill. Her nephew brought her to Michigan to live with him; after a bout of pneumonia, Miss Thomas was placed in a nursing home. She viewed this move as an insult – she felt that she could still live independently. Miss Thomas refused to leave her room for activities, declined one-on-one visits, and became a loner. Her days were spent watching TV and looking

out her window. She often talked with anger about being forced to leave her home in Philadelphia, about people selling her belongings and taking her money.

Miss Thomas sometimes becomes agitated during personal care. She often refuses to take her medicine and insulin and does not want to change her clothes. Staff are concerned about this lack of cooperation and her increasing withdrawal and isolation. Often she will not sleep in her bed, choosing to sleep in her chair instead.

Miss Thomas can identify the lack of respect from some of the care staff. Though she has a significant short-term memory problem and lack of awareness of her need for assistance, she is quite articulate about staff approaches to her care and her desire to be more independent and respected.

Awareness and Feelings in Individuals with Dementia:

The Voices of People with Early Stage Dementia

We can learn a great deal about the experience of dementia from those who are still able to tell us what it feels like. We often use videos or excerpts from memoirs to hear directly from those who can express their feelings and insights about living with dementia.

It is important to point out to staff that **the people who live in or attend our programs are often farther along in the disease process and cannot clearly articulate the things that early stage people can.** However, we can take many of the thoughts and ideas expressed by those in the early stages and extend them to the people we work with. It is important to continually remind staff that our residents used to be able to articulate many of these things when they were earlier in the disease process.

Early Stage Videos

For staff in residential settings, seeing and listening to people in the early stages of

the disease can be very enlightening; they are usually impressed with the amount of insight and the discrepancy between how normal people look and some of their deficits.

There are two tapes that we use that interview people in the early stages of Alzheimer's disease. These tapes are a good way of helping staff understand what it feels like to have AD, and how they would like to be treated. These videos could be used in an overview session, in a communication session, or just as a general sensitization too. Ordering information for these videos is available in *Audio-Visual Resources*.

Alzheimer's Disease: Inside Looking Out shows a group of people in the early stages of dementia. There are men and women from age 44 to late 80s, discussing what their journey with Alzheimer's has been like and some of their concerns about it. This video shows both the range of feelings and the individuality of the disease, as well as some of the issues they share in common. (Length: 18 minutes. The last few minutes are about support groups and could be skipped.) **A four minute clip from this video is included on the Training Tape on the DVD.**

- What are your reactions to these people?
- Do they change some of your ideas about what it is like to have Alzheimer's?
- What feelings do the people with dementia express? (Make a list.)
- What do they say about how they wish to be treated? (Make a list.)

Early Onset Memory Loss: A Conversation with Letty Tennis is a video of Letty Tennis and her family, discussing what life is like for her in the early stages of Alzheimer's. Because Letty is young and has an early stage diagnosis, staff may have difficulty imagining her as a future resident. It is important for staff to remember that

most of the residents they now care for went through this early stage of the condition. (Length: 21 minutes, but can use 5-10 minute segments.)

- What are some of the feelings that Letty expresses?
- What suggestions does she tell us about how to communicate with her?
- What is her family feeling?
- What are some of the ways in which Letty's daily routines have changed?
- Can you imagine Letty as a resident here in three or four years? What might she be like?

Memoirs

In our training programs, we have also used several excellent memoirs and journals written by individuals in the early stages of dementia. We recommend that you purchase some of these for your staff resource library. See the Reference List.

You might also use excerpts of these writings in training. You could read short portions to illustrate your points, or copy a paragraph for staff to read and react to. We have included short excerpts and discussion questions in the Outline. Below is some background information for you about each of these books.

The earliest, Robert Davis' book, ***My Journey into Alzheimer's Disease***, tells his life story as a minister. In one particularly powerful chapter, (Chapter 7 – The Abnormal Changes So Far) he discusses in detail what the experience of living with dementia is like for him. In another chapter, he discusses how his spirituality has been affected by having Alzheimer's disease.

Richard Taylor's book, ***Alzheimer's from the Inside Out*** is a series of short essays by a retired psychologist, in which he describes his experiences with daily life, diagnosis, traveling, giving talks, physicians, and many other aspects of his life with dementia.

Cary Smith Henderson, in *Partial View: An Alzheimer's Journal*, graphically and intimately describes what it is like to begin to lose one's own sense of history. His book is a little different in that it is a combination of powerful photographs of him, accompanied by transcripts of his thoughts and comments.

Lisa Snyder has written a book entitled *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's*. She includes pieces of interviews with seven individuals of various ages and backgrounds, poignantly expressing their thoughts and feelings about what it is like to have Alzheimer's disease, to live with it day to day, and to cope with its impact on their lives. The author provides some background and reflection on the experiences of the people as well.

Robert and Anne Simpson in *Through the Wilderness of Alzheimer's: A Guide in Two Voices*, provide a couple's perspective on his experience in the early stages of the disease. Often the same event is discussed by each, offering an opportunity to understand the complexities of couples living with Alzheimer's. At the end of the book, Bob and Anne each provide suggestions for coping from their own perspectives.

Experiences of Individuals in Middle and Late Stage Dementia

Many people in the early stages of dementia have a great deal of insight and awareness of what is happening to them. In talking about people's experiences in the middle stages, it is important to acknowledge the increasing problems people are having expressing themselves verbally. Their comments become shorter and vaguer in content; nevertheless most people have some awareness of what is happening to them, at least part of the time. A number of individuals with dementia have said things like, "I am going crazy" or "I am losing my mind" to describe their experience. We

believe that most moderately impaired people are aware on some level that something is wrong. We also believe that with enough time and encouragement, most moderately impaired people can tell us something about how they are feeling and what they need.

In residential care settings persons with dementia may ask staff about what is happening to them and why they are here "with all these crazy people." Staff need to understand the emotional struggles residents are experiencing as they try to make sense of what is happening to them. It is very important to teach staff how to respond empathetically in these situations.

By advanced or late stage dementia, people are rarely able to express directly what they are experiencing because their verbal skills are significantly compromised. **However, they can usually express their needs and feelings non-verbally in a variety of ways.** (Session 6 addresses this issue in more detail.)

Staff in training sessions have frequently asked us, **"Is the essence of the person still there in advanced dementia?"** This is a very difficult question to respond to, and there is a lot of controversy among health care professionals. Many of us have had experiences with residents in the late stages of dementia who have short moments of clarity and recall which allow their former personalities to emerge briefly before being submerged again. Sometimes a person may have made no coherent conversation for weeks or months and then suddenly he or she speaks or nonverbally demonstrates an awareness that takes us completely by surprise. Learning to identify and interpret non-verbal communication becomes critical.

We strongly believe that it is important to convey to staff that since we don't know how much awareness is there, **it is best to assume that the person, at least**

some of the time, can still understand you. Caregivers are becoming more sophisticated in looking at ways to make nonverbal connections with people in late stage dementia. Music therapy, validation therapy, massage therapy, and sensory stimulation are modalities that are being used to help individuals with late-stage dementia creatively express themselves.

Most importantly, we need to remember that people with advanced dementia can still display the human qualities of “faith, hope, and the will to live and love.” (Cohen, p. 7) The core of the person’s humanity is still there. While the person may have lost the ability to think, the emotional memory of the person is still there in the final months and days of life. We need to help staff learn how to recognize the emotions being expressed, to interpret what the person is feeling and wanting, and to respond in appropriate ways.

How do we help staff learn to recognize and respect the humanity of the person with dementia?

This is not easy. Perhaps the most difficult part (and the most important!) of dementia training is teaching staff to be empathetic – the ability to put oneself in the shoes of someone living with dementia. Some people do it easily and naturally; for others this is a struggle. In these training sessions, we need to explore ways to challenge staff to think about where they are in terms of their own level of empathy.

- How can we as trainers build into these sessions opportunities for self-reflection?
- How can we challenge staff to explore their own biases and attitudes about older persons with dementia?
- How willing are staff to get involved in personal relationships that are emotionally intense and complex?
- How willing are staff to stand up for what they believe is quality care?

As trainers and coaches, we must find multiple ways of addressing these issues, to continually remind ourselves and our staff that respect and compassion for the person with dementia come first.

Materials on the CD for this session:

Staff Handout on Humanity of the Person

Sample Family Story

Imagine Exercise #1

Imagine Exercise #2

Getting to Know the Person with Dementia:

Suggested Questions

SESSION 3

OUTLINE FOR TRAINERS

Respecting the Humanity of the Person with Dementia

Introduction

“It is important to know what disease the person has, but it’s more important to know what person the disease has.”

Dr. William Osler

Recognizing a Person’s Essence or Core Qualities

What makes each of us who we are? That question is an important one as we think about caring for people with dementia.

Why is it important?

- Because all of us want to be treated as individuals – as the unique people we are.
- Because people with dementia still have the essence or core qualities that have defined them, but we need to learn how to identify these qualities.
- Because if we can identify the core qualities of a person with dementia, we can build a more meaningful relationship with that person.
- When we can relate to who that person really is, we are more likely to be successful in doing tasks with them.
- The person with dementia will feel better about themselves and about us.

Dorothy Luther Vignettes

Introductory comments: I would like to introduce you to Dorothy Luther, a resident in an assisted living program. I am going to show you a short clip of her and would like you to think about this question, “Who is Dorothy Luther?” What are the qualities that you see in her? Don’t focus on her dementia – focus on who she is.

Video Vignette #1 of Dorothy Luther

In this vignette, we see Dorothy Luther folding napkins for an afternoon tea that is being held at Huron Woods for some women from a local church.

- What did you learn about Dorothy Luther from this videotape clip? What would you say are her the qualities or characteristics that make her who she is? What are her strengths?

Possible responses (This is not an exhaustive list. Write staff answers up. It may take an example to get them started): Core qualities that could be identified here include:

Precise – each napkin is folded identically to the others;

Social – enjoys the camaraderie with Anne; Likes to be busy – keeps herself engaged the entire time;

Likes to be recognized – is used to be helpful.

Very verbal

Able to initiate and continue task with cuing

Able to follow instructions

Comments: As a minister’s wife, Dorothy spent many years organizing and hosting social gatherings for members of their church. Identifying ways to engage Dorothy in meaningful occupation became an important focus of her care plan. When a social engagement was planned, Dorothy was often invited by staff to help prepare food and set the tables.

Video Vignette #2 of Dorothy Luther

In this vignette Dorothy and a staff member are setting the table in preparation for lunch.

- What did you learn about Dorothy Luther from this clip?

Possible responses include:

Likes to be busy.

Work ethic – a very powerful motivator for Dorothy.

Knows her own mind –is always clear about how she thinks should be done.

Good spatial skills – recognizes that a chair is missing

Problem-solving skills – recognizes that there must be an empty spot and finds it.

Good stamina –takes a lot of energy for Dorothy to do this task.

Good mobility –appears to be able to move well.

Good fine motor skills.

Precise – Dorothy is very precise about where to put each item.

Wants to get things right – She has strong feelings about the way things should be done.

Comments: The staff member is low key and focused on encouraging Dorothy to do as much as possible by herself. Note that she isn't hovering over Dorothy or jumping in to tell her what the next steps are. She gives her plenty of time to figure things out and acknowledges a job well done.

Video Vignette #3 of Dorothy Luther

In this vignette, we see Dorothy and her daughter, Anne, looking at old sheet music together.

- What else do we know about Dorothy Luther now that we can add to our list? Or what qualities do you see that are still evident?

Possible responses:

Interest in reading –can still read.

Talking/socializing –pleasure in the interaction with her daughter.

Social skills reasonably intact.

Awareness still good –aware of both the music and her daughter.

Looking at interesting things –still able to focus on the pictures and words, even though she may not know it is sheet music.

Vision still good.

Getting things right – at one point says, “If you think that’s really right.”

Fine motor skills still mostly intact.

Still able to express herself verbally.

Life Story, written by Dorothy’s daughter

Now let’s look at a story of Dorothy Luther’s life written by her daughter, Anne.

Pass out or read aloud Staff Handout: Who was Mrs. Dorothy Luther? Read the story aloud with staff following along. Show the photographs of Dorothy Luther from different times in her life. (Photographs and handout are on the CD.)

- What else can we add to our list of core qualities now?

Put up the powerpoint slide with the core qualities identified by her daughter, Anne.

Dorothy Luther – Core Qualities as defined by her daughter

- Feels capable, self-reliant.
- Believes there is a best way to do a thing. Believes that she knows the best way to do things. Therefore needs time to do things her way.
- Energetic, a hard worker.
- Focused on others – loves to help, enjoys being with others, companionship important, sense of community.
- Love of beauty – home, nature, people’s clothing, smiles.
- Love of words – of reading to others, of rhythm, of singing.
- Enjoys the out-of-doors – nature and being active important.
- Loves animals, pets.
- Sense of adventure.
- Enjoys life!

Using this information to provide better care

Now that we know a little bit about Mrs. Luther – what has been important to her, what she likes and dislikes, some of her abilities – let’s think about how you could use this information if you were providing care to Mrs. Luther.

- What day-to-day activities might Mrs. Luther especially enjoy?

We can learn from Mrs. Luther's history that she might enjoy a wide range of activities, such as:

Out-of-doors – Take her for walks; help her sit indoors where she can look out a window at pleasant scenery.

Cooking and food – Let her stir cookie batter and sprinkle colored candies on cookies.

Being with people – Invite her to sit in the living area near others; ask her to read aloud to others or share a book with someone.

Music – Ask her to join in sing-alongs, especially old songs and hymns

Books – Find a Bible, old hymnbook, or poetry book to read with Mrs. Luther or have her read aloud.

Pets – Try to have companion pets for her to enjoy: birds, a cat, a dog, or she may appreciate a stuffed animal to cuddle and tuck in bed.

Children – Have children visit from a day care program. Mrs. Luther would enjoy looking at picture books or cooking or singing with them.

Adventure – Take her on little field trips: to a farmers' market, a park, a quiet informal restaurant, a simple picnic.

- **How might we approach and interact with Mrs. Luther in ways that would make her feel at home?**

Invite her to sit with others to do something enjoyable.

Look at a picture postcard collection or a book of photographs.

Sit with her and observe together what is going on.

Use a light touch – try to pick up on her sense of humor and fun.

Invite her instead of insisting, "Mrs. Luther, will you have another cup of coffee with me?"

Ask her to help.

- **How can we help her maintain her considerable energy?**

Take her for walks several times a day, outdoors, if possible.

Design exercise programs that use her upper body as well. Organize exercise routines that are fun and colorful – using scarves, shaking maracas or tambourines, swinging arms in time to music.

Talk to her about her home when she wants to go home.

Look at photo albums with her. This can be a way to refocus her.

Find ways to involve her in activities assisting staff.

- **How might we build on Mrs. Luther's enjoyment of helping others?**

Invite her to help at mealtimes, setting the table, folding napkins, help cook or prepare fruits and salads when possible. Ask her to help staff fold laundry, such as towels and washcloths.

Invite her to help wash dishes, even though they may go into the dishwasher later.

Invite her to keep housekeeping staff company as they vacuum, take out the trash, etc.

Arrange for her to help other residents with tasks such as pouring juice for others, taking someone else for a walk down the hall, combing someone's hair, helping another woman try on jewelry, reading to others.

All of these things would **help Mrs. Luther feel she is making a contribution**, that she has something of value to offer.

This information should be built into Care plans, in language that is clear and reflects who the person is and was. Often Care plans are written in language that is full of jargon or not very specific. Let's look at an example and then we'll talk a bit about Mrs. Luther's Care plan.

- **How could we build what we know about Mrs. Luther into her Care plan? What approach to ADLs might we take with Mrs. Luther, recognizing her**

independent spirit and her belief that she knows the best way to do things? Take enough time so that she can do some of her own tasks, such as dressing.

Try giving her clothing, one item at a time and letting her do as much as she can – buttoning her own blouse, tying her shoes, choosing her own jewelry to go with an outfit.

Use a light touch – perhaps sing a little jingle she knows while she dresses to help her relax.

Watch and listen carefully for cues that she may give; if she feels hurried, she will refuse to continue.

Try to make this a warm, pleasant time for her – that feeling will persist later in the day.

In many settings Mrs. Luther would be labeled as “agitated” because of her high energy and need to be busy. Knowing who she is and designing activities that fit her will help avoid this kind of negative label. And, even more important, will help her feel better about herself and more connected to life.

- **Mrs. Luther’s adult life was devoted to her role as a minister’s wife, Sunday school teacher, and mother and she loved church music. How can we use this information into Mrs. Luther’s Care plan to help when she is agitated?**

Singing “Jesus Loves me” with her often helps calm her.

Reading the Bible may be calming, especially if staff know some of her favorite passages.

Being able to hold a Bible, a hymnbook, or other things that were important in this role.

Singing or reciting prayers or psalms during personal care may be helpful.

Who are you? Helping staff think about their own core qualities

Trainer: Choose either Method 1 or Method 2.

Method 1. Let’s think for a moment about our own core qualities. Take a piece of paper and write down 3 qualities that best describe who you think you are. Think of these as 3 qualities that you would like to be remembered for after you have died.

- Let’s make a list of some of the core qualities that you have written down about yourself. (Make a list and discuss.)

Method 2. We are going to do an exercise to think about our own core qualities. Take a piece of paper and write your first name vertically. Using each letter of your name as a guide, write down some of your qualities. Here is an example. (**Trainer: Write one of the examples below on newsprint or the board to illustrate.**)

D...demanding, delightful, likes dancing

Y...young at heart, youthful

L...loving, likeable, loud, loves music, food, parks

A...able to love and be loved, aggressive, easily agitated

N...nice, needy, naughty

J...joy of faith, uncompromising faith – NO religious debates

U...USA-patriotic, respect for civil service – NO politics

L...loves others unconditionally, loves dogs, gardening

I...independent, strong willed

E...enjoys giving, not receiving, enjoys mornings, needs eye contact

Concluding comments:

- Most of us did not write down memory as one of our core qualities. We are more than memory, and it's not our memory skills we want people to be focused on when they think of us.
- Even though Mrs. Luther's memory became impaired, the essence of who she was continued to be evident. Much of the essence or core qualities of the person with dementia remains intact and observable.
- We have to figure out ways of identifying the core qualities in the people we work with and use that information in individualizing care for them.

Imagine exercises

Introductory comments – Imagine exercises

Today we are going to talk about the experience of living with a condition such as Alzheimer's disease. It is not an easy thing to imagine what it feels like to have dementia, and perhaps something that none of us really wants to think about.

However, the more we begin to understand what it feels like to be a person with dementia, the better able we are to provide individualized and compassionate care.

Trainer instructions:

Start by relaxing, closing your eyes, get comfortable in your seat.

(Give them a moment or two to relax and get comfortable. Read slowly and with feeling.)

Let's imagine for a moment what it would be like to have memory loss and not be able to think or process information very well.

Read Imagine exercise.

Imagine Exercise #1

by Jitka Zgola.

You have some memory of having done things, pleasurable things, worthwhile things, rewarding things, necessary things, things for which people praised you or thanked you. You still have a lot of energy to do things, but now there is nowhere for you to direct that energy because there is nothing that you can do. When an instrument falls into your hands, a dish towel, a rake or a pair of scissors, for example, your hands seem to remember what to do with it. At those times it feels good. You get into the rhythm of the job. Your joints and muscles respond and the movement feels terrific! You are making something happen! You are making a difference!

Too many times, though, things do not work well, things end up spoiled. Sometimes people scold you or simply ask you "What did you do that for?" You don't know. You just know that you were trying to help and somehow things went wrong. At other times someone asks you to do something and you just can't figure out how to do it. You want to help but you just can't get things together. Then they think that you are difficult.

It's embarrassing. It's painful; and if it happens often enough, activity becomes something to be avoided. You learn to avoid the pain by just staying out of things. That leaves you in a limbo of inactivity, lost, with nothing to do, no significant special role, causing nothing, controlling nothing and needed by no one.

The most difficult thing to take, perhaps is the loss of control over your own things. It started when you could no longer drive the car or maybe when the banking got too difficult. It got worse when someone had to come in to clean the house and do your groceries or when they put your tools away for good or when you sat in your

kitchen, drinking tea that someone else had made and poured and eating cookies that someone else had baked. You sense that no one is going to praise you again for the baking that they used to love so much.

It will get a lot worse when you have to hand over your dentures for someone else to clean or when they have to dress you and feed you. It will get a lot worse when they give you a child's puzzle to put together or suggest that you might like to play with Legos. Deep inside you know that you are an adult, a responsible, competent taxpayer, no one's fool. Do they really think you have come to this?

Open your eyes and let's think together about what this experience felt like.

How do you feel with these things happening to you? (List all answers on the blackboard or newsprint.)

Examples of answers from staff:

- Feel useless, worthless
- Bewildered
- Vulnerable
- Angry
- Embarrassed
- Humiliated
- Frustrated
- Paralyzing panic
- Lonely
- Depressed
- Fear of being abandoned
- Fear of being lost
- Fear of being out of control

What do you need from staff to help you cope with these feelings

Emotional Needs

- To be loved
- To be able to express affection, touch
- To belong, be together with others
- To be able to contribute in a significant way to the community
- To be recognized and valued

- To express feelings of happiness, anger, frustration, sadness
- To feel a sense of comfort and security
- To be unconditionally accepted for who you are and what you have been
- To be able to experience moments of tranquility and solitude
- To be able to experience pleasure, enjoyment, and satisfaction

Physical Needs

- To be able to participate in exercise and movement
- To be able to receive ongoing evaluation of pain, discomfort, use of medications
- Comprehensive assessment to determine accurate diagnosis

Other Needs

- To have opportunities to participate in creative and spiritual expression
- To have a sense of purpose
- To be listened to
- To have my questions answered
- Sense of accomplishment
- To be able to express opinions, beliefs and values
- To be able to learn new things with the support of routines and structure
- To be able to make choices and decisions
- To be treated with dignity and respect
- To be independent and have some control over my life
- To be able to reflect on past memories and experiences
- To be able to live as normal a life as possible
- To be able to die with dignity and on my own terms
- To be supported by individuals who understand my needs

Training Tape Videos

Trainer: The background information on Irene Schwartz and Susie Thomas are in the Suggestions for Trainers. You may want to read that to staff before or after they've seen the videos, or to summarize key points for them.

Description of Irene Schwartz Video

Vignette #1

In the first video vignette, you will be observing Mrs. Schwartz participating in a discussion group. One of the group members, Edith, was a genealogist who had compiled a history of the Revolutionary War soldiers who lived in the area of Stamford, Connecticut. Edith's heritage was of Irish and English descent, her religion was Protestant. The conversation is focused on the topic of funerals. Edith and Irene have different religious backgrounds and different beliefs about what happens to the body at the time of death. This vignette is a lovely example of the potential for stimulating discussions with individuals with moderate impairments. Both women have excellent verbal and social skills and on first impressions it is difficult to imagine that they have the symptoms of dementia.

- What are Mrs. Schwartz's strengths?
- Describe the emotions displayed by Irene and Edith.
- Knowing the life story of each person in your program is important. Do you have background information similar to the above description for each of your residents? If not, how you could you and your co-workers begin to gather this information from families?
- Our tendency is to sometimes underestimate the abilities of people with dementia.
- How might you build in conversations like this into your day-to-day interactions with residents?

Description of Irene Schwartz Video

Vignette #2

In the second vignette, the same group is involved in a service project. They are folding invitations for a local university that is hosting a reception. The group members have volunteered to fold the invitations and to put them in envelopes. Mrs. Schwartz is seated to Gwyn's left. Gwyn is explaining to Mrs. Schwartz what needs to be done. At

the same time, she is demonstrating how to fold the invitation. You will see that Mrs. Schwartz is having a lot of difficulty trying to figure out how to fold the invitation into thirds.

- What are some of the strengths Mrs. Schwartz has?
- What are some of the difficulties Mrs. Schwartz is having?
- Describe Mrs. Schwartz's mood.
- How might you help her be successful with this task?
- How could the concept of residents assisting with a service project be incorporated into your program? What groups in your community might you contact?

Description of Susie Thomas Video

Vignette

Jo, the staff member in the video, had been visiting twice weekly with Miss Thomas for several months—building a relationship and friendship. Miss Thomas began to tell Jo about her concerns and was very interested in being interviewed and taped. She was excited about educating others to the needs of nursing home residents and was sure to dress up for the occasion. The tape demonstrates Miss Thomas' verbal capabilities, but her short term memory problems – though they exist – are not apparent in this short segment.

- How do you think you would feel if you were Miss Thomas?
- Why do you think she chooses to stay in her room and not participate in activities?
- What are some reasons she sometimes becomes agitated during personal care?
- What can caregivers do to make assistance with her care more acceptable?

The Voices of People Diagnosed with Early Stage Dementia

We can learn a great deal about the experience of dementia from those who are still able to tell us what it feels like.

Many of the individuals in our program may no longer be able to verbally express their feelings, needs and reactions as clearly in words as the people who are in the video we are going to see (or who wrote the memoirs I'm going to read excerpts of).

Use an Early Stage Video here (See *Suggestions.*)

Memoirs

Several people have written books about what it feels like to live with Alzheimer's disease. We are lucky to have people who are brave enough to share their experiences to the world, so we can learn. I am going to read you some of their thoughts for us to talk about.

This is from Robert Davis' book, *My Journey into Alzheimer's Disease*. He was a minister who had to retire because his memory loss began to interfere with this day-to-day living.

"In my present condition...there are times when I feel normal. At other times I cannot follow what is going on around me; as the conversation whips too fast from person to person and before I have processed one comment, the thread has moved to another person or another topic, and I am left isolated from the action--alone in a crowd. If I press myself with greatest concentration to try to keep up, I feel as though something short circuits in my brain." (p. 85-86)

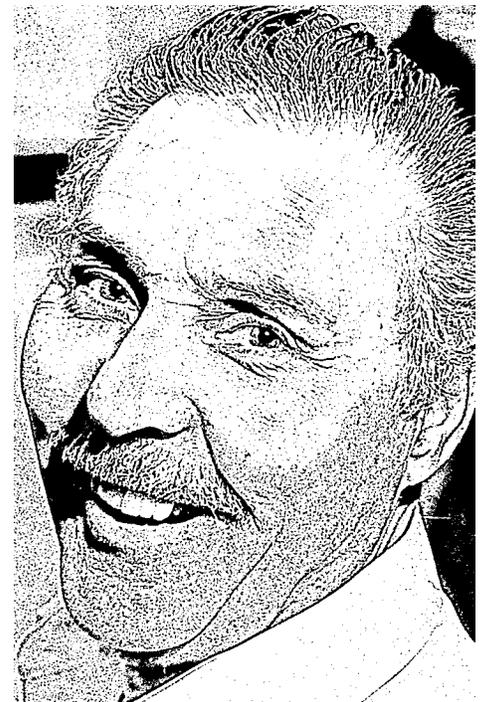
- What are some of the feelings and frustrations expressed in this excerpt?
- What does it mean for how we as caregivers should communicate with Mr. Davis?

This is from Carey Smith Henderson's book, *Partial View: An Alzheimer's Journal*.

"I've been at this Alzheimer's thing quite a while now. I don't enjoy Alzheimer's. I'll say that for you, for me – but there's something in it that I feel rather at home with people with Alzheimer's.

I think one of the worst things about Alzheimer's is you're so alone with it. Nobody around you really knows what's going on. And half the time, most of the time, we don't know what's going on ourselves. I would like some exchange of views, exchange of experiences, and I think for me at least, this is a very important part of life..." (p. 55)

- What are the feelings being expressed by Carey Henderson?
- If you suspected someone felt this way, what are some things you could do to help?



SLIPSHEET

Session 4: Adapting Our Methods of Communication

Beth Spencer and Anne Robinson

Interactive Training Strategies

- Discussion questions with powerpoint slides. Use these to structure a brainstorming session on communication strategies.
- Four case studies. These are included to promote discussion on specific types of communication problems.
- A video clip of Sarah Campbell, an assisted living resident, during an interaction with a staff member. Background information and discussion questions are included.
- A video clip of John Porter, a nursing home resident, being invited to a Dinner Club by a staff member. Background information and discussion questions are included.
- Videotape clips from several commercial productions.
- Role-plays. Three role-plays of different kinds with directions are included at the end of this section.

SUGGESTIONS FOR CONDUCTING SESSION 4:

Adapting our Methods of Communication

The goals of this session are:

- To help staff think about how to develop meaningful relationships – including the ability to build trust and rapport – with individuals with dementia.
- To introduce staff to the idea that one of the key elements in success with people with dementia is creating a positive, calm, supportive mood.
- To teach staff how to adjust their communication styles when individuals are having trouble finding the words to express themselves and comprehending what staff say.

Learning to communicate well with older adults who have Alzheimer's disease (AD) and related dementias is a key part of working effectively with them. Poor communication often leads to the person becoming agitated, upset, or angry.

Building relationships between staff and those with dementia is perhaps the most important element of communication. We will begin with a discussion of that, and then discuss strategies for teaching communication techniques.

Building Relationship with Individuals with Dementia –

Why this is important

The idea that relationship-building is key to good communication relates back to many of the points we discussed in the session, *Respecting the Humanity of the Person*. These include the importance of:

- Creating empowering environments for individuals, where there is respect for the individual person, his or her history, and unique qualities.
- Teaching staff how to develop meaningful personal relationships with people with dementia, and making it acceptable and essential for staff to spend time this way.
- Emphasizing relationships and the process of interacting.

Often, staff members will be far more successful in assisting an individual with his or her care if they have taken the time to get acquainted with the person and to develop rapport. Even though it takes time to build and nurture relationships, it often saves time in other ways. When staff rush into tasks and focus on completion of tasks rather than building a relationship, they often meet resistance, resentment, or incomprehension. The person with dementia may be left with a lingering sense of anger or distress even though he or she may not remember the actual event. Ultimately, trying to communicate or complete tasks with a person who is resistant or angry takes more time than spending additional time up front nurturing the relationship. And it is a much more respectful way to begin an interaction.

But the real reasons to help staff with this piece of the communication process are

- To enhance the quality of life and self esteem of individuals with dementia, and
- To enrich traditional staff roles and encourage the part of the job that is often most rewarding.

A number of the authors we discussed in *Respecting the Humanity of the Person* have elaborated on the power and importance of relationship building. Virginia Bell and David Troxel (1997) in *The Best Friends Approach to Alzheimer's Care* use the analogy of “being a best friend” to

a person with dementia to address many of these issues. They have developed a number of “Elements of Friendship and Alzheimer’s Care” (pp. 44-62), which include approaches such as learning the person’s moods and personality, being their memory when need be, knowing their history, laughing with them, treating them as equals, etc.

For some staff, the idea of being a “best friend” may be an excellent way to help them with relationship-building. Bell and Troxel’s model is a very concrete way of helping staff think about relationship building. Their book is an excellent resource for a staff library and to use in staff training; it is easy to read and written for the lay person.

For those trainers wishing a more philosophical approach, Tom Kitwood’s work (1997), *Dementia Reconsidered: The Person Comes First*, is an excellent starting point. Although we have listed a few of his ideas below, trainers with an interest in this area are encouraged to read his work in its original form. His work is much less accessible to the lay person and will need interpreting and examples for staff.

Kitwood (1997) devoted many pages to what he called “Positive person work” (p. 89). He discussed twelve elements of relationship building, including the following:

- *Recognition* – The caregiver brings an open and unprejudiced attitude, free from tendencies to stereotype or pathologize, and meets the person with dementia in his or her uniqueness.
- *Negotiation* – The caregiver sets aside all ready-made assumptions about what is to be done, and dares to ask, consult and listen.
- *Collaboration* – There is a deliberate abstinence from the use of power, and hence from all forms of imposition and coercion; ‘space’ is created for the person with dementia to contribute as fully as possible to the action....

- *Relaxation* – The caregiver is free to stop active work, for a while, and even to stop planning. He or she positively identifies with the need that many people with dementia have: to slow down, and allow both body and mind a respite.
- *Validation* – The caregiver goes beyond his or her own frame of reference, with its many concerns and preoccupations, in order to have an empathic understanding of the other; cognitions are turned down, and sensitivity to feeling and emotion is heightened.” (pp. 119-120)

Helping Staff Build Rapport with Individuals with Dementia

We have provided a number of different ways to address this issue of building rapport, including:

- A section in the *Outline* on building rapport. As part of communication training, these are points we review with staff. Working through these points and thinking about how to implement them in your setting is important.
- A case study that addresses this issue, Case Study 4-C. We encourage you to use this with staff to help them begin to think about what it means to have a positive connection with someone with dementia.
- Use the sources cited above, Bell and Troxel, and Kitwood. Dan Kuhn (2003) also has a helpful chapter on communication issues with people in the early stages of Alzheimer’s disease. You can create your own overheads and discussion questions using any of these sources.
- Videotape vignettes. We have included two on the Training Tape, described a little later in this section. There are also several excellent commercial videos, described under Other Videotapes later in this section.

- Role-plays are often a good way to teach staff about building trusting relationships with people with dementia.

Communication Change over Time

As we train staff, another important thing to think about is how the person's process of communication changes over time, and how our communication patterns have to change in response. In the *Outline*, we have included a story that addresses this issue and a series of overheads that demonstrate visually how our communication has to change. Reading the story and then reviewing the overheads will help staff begin to understand this issue. Using examples from your own program for each overhead will also help make this concept clearer.

The best way to support a person with dementia as the disease progresses is to begin with a strong, meaningful relationship. In our programs and services, we do not always have that option.

Sometimes people enter the system at a point where their verbal communication skills are poor and family members are not available to fill in the gaps. But we need to learn as much as possible about who the person is and was – through observation, history from the person and the family, photos, and conversation. The more we know, the more we will be able to support them.

Using the *Outline*

We often spend several training sessions on communication. As with other sessions, you can pick and choose what works best for you and your staff. One way to begin to think about teaching relationship building is to use the information developed by one of the authors above and work through those elements with your staff.

Another approach is to watch the video vignettes discussed below and discuss ways to gather important information about individuals in your program. Some things you might discuss with staff include:

- What information do we have or not have about the people we work with? Think about their past history, cultural, ethnic, or racial background, likes and dislikes, hobbies, important events, personality style, daily life, etc.
- How accessible is this information to direct care staff, who need it the most?
- How do staff members make friends outside of work? How might they apply some of these techniques to their work with people with dementia? What is the same or different?

Discussion Questions

One way of approaching communication is to cover the communication techniques in the *Outline*. The points on the *Outline* are summarized on the transparencies and in a handout for staff. We have found that it is effective to lead a discussion and have staff come up with the strategies themselves, before using the powerpoints or handouts. Then list and discuss their answers.

- When you are talking to a person who is confused or forgetful, what are some of the things you do that seem to help? Speaking calmly, sitting and chatting for a few minutes before asking her to do anything, introducing self.
- What do you say or do when the person with dementia doesn't seem to understand you? Repeat the sentence again, demonstrate visually, change the subject and come back to it later.
- What do you say or do when you can't understand what the person with dementia is trying to say? Give an example of a resident who cannot express herself clearly. Pick out one clear word and repeat it, try to respond to the feeling instead of the words, use touch.
- Are there things you've tried when you were having trouble communicating with a person with dementia that have made the situation worse? Arguing, ordering the person around.

- Suppose a resident or program participant with dementia says to you, "I have to go home now. My mother is waiting for me." What are some ways you might respond? "I don't think your mother is here right now. Let's go get some coffee."

This is an area where you may want to talk about how residents feel when we say things like, "This is your home now." or "Your mother has been dead a long time." We have included some points about this in *Outline, Talking About Things That Aren't Real or True*. Case Study 4-D also addresses this issue.

Case Studies

Often we combine some of the material from the background outline with the use of a case study. Included at the end of this session are several Communication Case Studies. For suggestions on using case studies see *Training Staff: Issues to Consider*.

Case Study 4-A helps staff understand what it feels like to have to go to the bathroom and ask strangers for help. Case Study 4-B describes a situation where a resident of a nursing home is overwhelmed at meal time. Staff can use this to think about communication strategies in this situation. Case Study 4-C raises the issue of establishing rapport with a resident before trying to engage him in a task. Case Study 4-D gives staff the opportunity to have a structured discussion about truth-telling and reality when a person is waiting for her dead husband.

Role-plays

Role-plays can be a very effective way to demonstrate communication do's and don'ts. There is a discussion of the use of role-plays in *Training Staff: Issues to Consider*.

In this session we have included several ways to do role-plays:

- One way is to use a script. You can write your own, based on interactions you have seen in your program. It is often most effective to demonstrate a poor approach first. You will need a partner to play one of the roles with you. Write down a simple dialogue between a staff member and resident, that illustrates all the wrong approaches by the staff member. It helps for you and your partner to practice the role-play several times before the inservice. There is a sample script at the end of this session.
- Communication role-plays focus on the interaction between staff members and a person with dementia. It might be a staff member trying to get a person up or to agree to have a bath. Or it might focus on eating or toileting problems. You might include the staff member turning the radio on loudly, or shouting to another staff member; the staff member could move too fast, try to put the person's glasses on when she is unaware, etc. You can have the person be non-verbal, or verbal but incomprehensible, or verbal and stubborn. Gradually as the staff member gets more frustrated, the person gets angrier or more resistant. **It is very important not to be disrespectful in our portrayals of persons with dementia, to be careful not to exaggerate too much or make fun of their inabilities.**
- Another approach to role-plays is to use volunteers from the group of staff and give them a scene to act out for the rest of the group. At the end of this session are two other sample role-plays, where the set-up and scene are described, and the trainer uses staff volunteers to enact it. Directions are included.
- You can do the role-play, have a discussion with staff about some of the poor approaches, and either list

better approaches, or demonstrate a good approach. Demonstrating is a very good way of modeling the kinds of communication approaches we want staff to use.

Videotapes

Communication Vignette #1 – Sarah Campbell Training Tape

Background information about Sarah Campbell

Mrs. Sarah Campbell was born in a small town in Iowa in 1908. She was the child of Russian immigrants and her parents were religious Jews. As a young child, Mrs. Campbell developed a gift for music and became a child prodigy pianist. She attended the University of Michigan where she met her husband, a professor. They had one son who has also pursued a music career.

Mrs. Campbell loved to perform and was very active in amateur theater, particularly focusing on modern dance and ballet. Mrs. Campbell had a wonderful sense of humor and could be quite playful and dramatic at times. She enjoyed mime, and her hand and facial gestures were often very striking. In addition to theater, she taught piano lessons and played accompaniment for ballet recitals. She also loved art, both classic and contemporary.

Mrs. Campbell was well known for the musical parties which she and her husband hosted in their home. They both had baby grand pianos and played jazz, classical and show tunes. Friends, students, colleagues and neighbors coveted invitations to their home. She loved to cook gourmet foods for these events.

Mrs. Campbell had a gift for flower arranging. She loved vivid colors, textures and smells. She appreciated elegance and fine things. An immaculate housekeeper and organizer, she kept many detailed lists, outlining tasks to be done. She was the ultimate perfectionist, wanting things to be done in a particular way.

In the mid 1980s, Mrs. Campbell was diagnosed with progressive dementia. Her husband took care of her for several years at home. In 1990, she moved into Huron Woods, an assisted living home specializing in dementia care. She died in 1996.

Description of the Video Clip

In this vignette, Mrs. Campbell and a staff member are interacting one-to-one in a small room off the main living room. As her cognitive abilities continued to decline, staff were challenged to find meaningful experiences for Mrs. Campbell. Most of the large group programming offered throughout the day were overwhelming. This staff member decided to design a series of one-to-one interactions, focusing on ways to enhance Mrs. Campbell's creative expression. Since her verbal abilities were significantly impaired, the activities centered on music, exploring fabrics, jewelry and buttons, baking bread and smelling different spices.

Because Mrs. Campbell loved beautiful things, the staff member put together a few carefully selected fabrics of different colors and textures which they could explore together. The staff member wanted to use the fabric to connect with Mrs. Campbell and to encourage her to creatively express her feelings, both verbally and non-verbally.

- Identify some of Mrs. Campbell's remaining strengths and abilities.
- What are some of the techniques the staff member uses to verbally communicate with her?
- What are some of the non-verbal methods of communication used by the staff member? How might you use these techniques when interacting with some of the people you work with?
- Describe the quality of the relationship between Mrs. Campbell and the staff member.
- Describe the benefit of this interaction for Mrs. Campbell.

Communication Vignette #2 – John Porter Training Tape

Background Information about Mr. John Porter

Mr. John Porter has lived his past five years in a Michigan nursing home. There is not much information available in his records about his early life, but his long-term memory is strong. Mr. Porter remembers being born 89 years ago in rural Alabama. His “mama” was a wonderful cook and he recalls some of the special dishes she prepared. John and several brothers and sisters lived on a farm. He talks about growing watermelon, beans, peas, cabbage and turnips. Mr. Porter chuckles as he tells us, “Mama was tiny, but she could sure “wup” me when I got out of line”.

Mr. Porter has a diagnosis of progressive dementia caused by strokes and is moderately impaired. He needs a great deal of assistance with ADL’s and meal set-up, as his left side is paralyzed. Mr. Porter’s long-term memories about life in Alabama as a young man are vivid. He has a wonderful sense of humor, is an incredible conversationalist and loves jazz, blues, and dancing. He is very complimentary and appreciates being invited to the Dinner Club.

Mr. Porter is a member of a Dinner Club that meets weekly. There are two tables comprised of a women’s group and a men’s group. The members of the Dinner Club were chosen by the staff because they are at risk for weight loss and/or are demonstrating challenging behaviors at mealtime. The normal mealtime environment is confusing and not set up to meet their special needs. The Dinner Club was formed to address these concerns. Interventions have been developed to encourage the group members to eat independently, by providing some finger foods and a calm, relaxed environment.

Description of the videotape clip

In this vignette, Mr. Porter is seen arriving

at the door of the room where the Dinner Club meets. The staff member greets him warmly at the door, invites him in and escorts him to his place at the table.

- What does the staff member do to help Mr. Porter feel welcome as he first enters the dining area?
- How does the staff member orient Mr. Porter to the fact that it is supper time and they are going to be sharing a meal together?
- How does the staff member introduce Mr. Porter to the other members of the Dinner Club?
- Describe the general atmosphere.
- How might you incorporate some of the staff member’s communication strategies into your mealtime program?

Communication Vignette #3 – Viola Training Tape

This vignette is on the DVD Training Tape by permission of the production company. It is from the Mental Health Series, discussed below. The Viola vignette is a conversation about memory and parents between a staff member and a very frail older woman. We use this vignette to talk about establishing rapport, dealing with issues of truth and reality, and the importance of gentleness and respect in conversation.

Other Videotapes

There are several other videos that we have found useful in teaching communication techniques. (For ordering information of others see Sources for Videotapes.) We often use these in combination with the discussion questions, or may use one of the videos during a follow up session.

Mental Health Series: Communicating with Moderately Confused Older Adults and Communicating with Severely Confused Older Adults. These two videos examine communication issues at the different stages of Reisberg’s Global Deterioration Scale. There are excellent examples

of real individuals in residential care settings interacting with staff, followed by experts from various disciplines discussing communication deficits and strategies.

In particular, there are several wonderful vignettes in the videotape *Communicating with Severely Confused Older Adults*. One shows a staff member waking up an older resident, who is sleeping in her chair. It is an excellent example to use as you discuss the idea of establishing a relationship before beginning a task.

In the video *Everyone Wins – Getting Hit, Grabbed, and Threatened: What It Means and What to Do*, which is also on the DVD Training Tape, there are a number of examples of staff approaching residents in a nursing home in ways that are unsuccessful, followed by more successful interventions. In most cases the more successful examples illustrate the importance of rapport, connection, and knowing the person.

Other Issues to Think About

There are many ways in which our ethnic or racial heritage affects the way we experience the world. When the people we work with are from different backgrounds from us, their communication styles may be quite different. Communicating with people with dementia can be challenging in itself; when there are racial, ethnic, or language differences in addition, it is easy to misunderstand each other.

Discussion of cultural, ethnic, and racial differences is beyond the scope of this manual. However, it is important for trainers to be aware of how these differences impact on care issues. Individuals with dementia may be unable to explain their heritage to staff, but information about it may help staff understand residents better. Inservices related to cultural beliefs and communication differences can be very useful.

Materials on the CD for this session

Staff Handout: Communication Tips

Case Study 4A: Relying on the Kindness of Strangers

Case Study 4B: Meal Time Difficulty

Case Study 4C: Building Rapport

Case Study 4D: Truth and Reality

Sample Role Play #1

Sample Role Play #2

Sample Scripted Role Play #3

Session 4 Outline for Trainer

Adapting Our Methods of Communication

Communicating with a person who has dementia can be a terribly difficult task. Often in **early stages** of dementia, people have trouble finding the words to express their thoughts, or may be unable to remember the meaning of simple words or phrases; but these problems are usually minor inconveniences or frustrations. **The later stages** may be much more difficult. In some individuals, language skills are quite impaired, resulting in garbled language that we cannot understand. Some people's comprehension is greatly affected, though many times they may understand more than we anticipate.

When people cannot comprehend what is being said, or cannot find the words to express their own thoughts, it can be painful, frustrating, and embarrassing for everyone. The following are some suggestions of things to think about when communicating with a person who has dementia.

Building Rapport with Individuals with Dementia

What does rapport mean? Rapport means building a harmonious or sympathetic connection with another person.

This is important in our work with people with dementia. To truly do a good job of communicating with a person who is confused, has memory problems, and may not understand us very well, we must begin by making a good connection, building rapport.

- **Before approaching the person, take time to reflect on your own mood and level of patience.** Are you able

to shift gears right now and focus on this person, who needs your whole attention, concern, and patience?

- **Consider the time of day, what you know about this individual, and adjust your style as needed.** If it is early in the morning and the person is still in bed, consider how you would want to be greeted as you are awakened. Many of us want calm and quiet first thing in the morning; a brisk or overly cheerful person is likely to upset us.
- **Acknowledge that it takes time to wake up.** This is true not only in the morning. Some people believe it is the next day when they awaken from an afternoon nap. Keep this in mind and adjust accordingly.
- **Respect privacy.** If the person is in the bedroom or the bathroom, knock and wait for a reply before entering. Softly greet the person through the door.
- **Assess the person's mood.** Go slowly and try to sense how the person is feeling. This is part of the process of building trust – understanding someone else's mood, validating it, and meeting the person "where he or she is at."
- **Spend the first few minutes quietly visiting.** Think about what you know about this individual: What does he or she enjoy? Are there pictures you can comment on? Hobbies? Use this time to make a personal connection with the person.
- **Offer a glass of juice or water.** Sometimes offering something to drink before you try to engage the person in a task is very helpful, especially following a nap or first thing in the morning.
- **Give the person a gentle massage, if this is appropriate.** This can be a way to help the person relax and establishes a connection.
- **Play music to help set a positive tone, if this is something the person enjoys.**

Use music that is familiar and of the type the person likes.

- **Approach the person as you would approach a friend** – smiling, friendly, warmly.

Your Approach - You Set the Tone

- **Think about how you are presenting yourself.** Are you tense? Frowning? Are you being bossy or controlling? People with dementia are often extremely aware of non-verbal signals such as facial expression, body tension, mood. If you are angry or tense, they are likely to become angry or anxious.
- **Try a calm, gentle, matter-of-fact approach.** You set the mood for the interaction – your relaxed manner may be contagious.
- **Use a non-demanding approach** – try humor, coaxing, calmness. Humor or gentle teasing sometimes helps caregivers through difficult moments. Convincing someone to get out of bed or go to the bathroom may be easier if you can make a game or joke of it. Ordering or demanding will be much less successful with most people. However, you must know the person – Does he or she have a sense of humor or will this antagonize?
- **Try using touch to help convey your message.** Sometimes touch can show that you care, even when your words don't, or when they are not understood. Some people shy away from being touched, but most find a gentle touch reassuring.

Things to Think About When You Speak

- **Talk to the person in a place that is free from distractions** such as equipment noise, television, or other conversations. People with dementia often have very little ability to screen out distractions.

- **Begin conversations with orienting information.** Identify yourself, if necessary, and call the person by name. After creating a relaxed atmosphere, explain what it is you propose to do.
- **Look directly at the person and make sure you have his or her attention** before you begin to speak. If you cannot get his/her attention, wait a few minutes and try again. Move slowly. Gently touch an arm or hand to gain attention, while saying the person's name several times. Be careful not to startle.
- **Be at eye level with the person,** especially when talking to people who are in the later stages or to those who are hard of hearing. In some cases, you may need to stand or sit much closer than you would normally be.
- **Speak slowly and say individual words clearly.** This is particularly important for people with hearing problems or those who are in the later stages of dementia.
- **Use short, simple sentences.** People with dementia may not be able to remember more than a few words at a time. Pause between sentences and allow plenty of time for the information to be understood.
- **Ask simple questions that require a choice or a yes/no answer,** rather than open-ended questions. For example, instead of saying, "What would you like to wear today?" you might say, "Do you want to wear this green dress or this red one?" or "Is this the dress you would like to wear today?"
- **Use very concrete terms and familiar words.** As people become more impaired they lose the ability to understand abstract concepts. Thus, you may need to say, "Here is your soup," instead of "It's time for lunch." They may also revert to words from childhood or earlier in life. "Do you

need to go to the bathroom?” may not be understood as easily as “Do you have to pee?”

- **Talk in a warm, easy-going, pleasant manner.** Try to use a tone of voice that you would like people to use with you.
- **Keep the pitch of your voice low and slow.** Sometimes when individuals with dementia don’t immediately understand us, we have a tendency to shout. This will simply upset them and will make communication more difficult.

When Doing a Task Together

- **Avoid saying anything about the task at hand** until you feel comfortable with the relationship you have established. Winning the person’s trust first can often make a task much simpler.
- **Begin with the first step** when introducing a task, instead of describing everything that will happen. For example, “Let’s take a walk together down the hall,” is very different from “It’s time for your shower.”
- **Try to focus on familiar skills or tasks.** People with dementia gradually lose the ability to learn new tasks, but may be able to do familiar work, hobby-related tasks, or household chores even when very impaired.
- **Give choices, whenever possible.** For example, choosing whether to take a bath before or after dinner or choosing which of two shirts to wear may help the person continue to feel some sense of control over life.
- **Allow plenty of time for the information to be absorbed.** People with dementia often need much more time to comprehend simple statements or instructions. Allow a moment of silence before repeating an instruction. This requires a lot of patience on the part of caregivers.

- **Try repeating instructions exactly the same way.** It may take a number of repetitions before the person responds. If, after allowing plenty of time, it still is not understood, try using different key words, or demonstrating what you want the person to do.
- **Break the task down into simple steps.**
- **Modify the steps** as the person with dementia becomes more impaired. You may need to break the task into even smaller steps, or you may need to begin doing some of the steps that the person was able to do previously. Again, this takes time and patience on the part of the caregiver, but can be very rewarding for both the person with dementia and the caregiver.
- **Praise sincerely for success.** We all need to hear that we are doing a good job, and for people who are losing their abilities it may be particularly important. Praise doesn’t need to be long or “gushy” but may be a simple thank-you, or “You did a nice job.”

When You Are Having Trouble Being Understood

- **Be sure you are allowing enough time.** It may seem to you that you have waited a long time, but people with dementia often need a great deal of time to process information.
- **Try demonstrating visually what you are saying.** Though not always possible, this technique of doing and saying at the same time is often a very effective way of communicating. Use visual aids – hold up the sweater when you are saying, “It’s time to put on your sweater.” Point to the spoon when you are encouraging the person to eat.
- **Think about the complexity of what you are saying.** Can you say it more simply? Is it too many words or too abstract for the person to understand? Can you be more concrete? Saying, “Why don’t you sit in this chair?” while

touching the chair, may be much more effective than “It’s time for breakfast.”

- **Try a hug and a change of subject.** If you are both getting frustrated, it may be a good idea to drop it for the moment and try again later. Sometimes a hug and change of subject can make you both feel better. Other times you may need to leave the room and calm down.

When You Are Having Trouble Understanding

- **Listen actively and carefully to what the person is trying to say.** If you do not understand, apologize and ask him/her to repeat it. Let the person know when you do understand by repeating it or rephrasing it.
- **Try to focus on a word or phrase that makes sense.** Repeat that back to the person and try to help him/her clarify what is being said.
- **Respond to the emotional tone of the statement.** You may not understand what is being said, but you may recognize that it is being said angrily or sadly. Saying, “You sound very angry,” at least acknowledges the feelings, even if you cannot decipher the words.
- **Try to stay calm and be patient.** Remember the person is not doing this on purpose and is probably even more frustrated than you. Your calmness and patience will help create a caring atmosphere that will encourage him/her to keep trying.
- **Ask family members about possible meanings for words, names, or phrases you do not understand.** Sometimes people with dementia talk in a kind of code that may make sense to people who have known them for a long time. A name called over and over may be a close friend or relative from the past whose memory is reassuring. “Let’s go down that street to my house,” may be a very logical way of referring to a long

corridor and room, when the names for these places have disappeared from memory. Language from childhood, such as names for bathroom habits or pet names for things, may reappear in the person’s vocabulary. While it is helpful to use their words (e.g., “pee” or “tinkle”), it is important to continue to treat them as adults, not children.

Talking About Things That Aren’t True or Real

Sometimes the person with dementia will talk about things that aren’t true or real. For example, a woman might say that her mother is coming to get her, when her mother has been dead for many years. Or a man may insist that there is a man sitting in the corner, when no one is there.

- **Remember that our reality is not their reality.** Because of changes in the brain, the person with dementia may no longer have the ability to understand what is real or true today and what is not. He or she may genuinely see someone sitting in the corner, even though no one is there.
- **Keep in mind that arguing or correcting people with dementia often upsets them.** It also does not usually work, as the person no longer has the ability to be logical about what is real and what is not.
- **Talk with them about what they see or feel in a supportive way.** Sometimes just listening is enough.
- **Try validating their feelings.** “You are missing your mother, aren’t you?” is often much more effective than “Your mother has been dead a long time.”
- **Try a straightforward answer** such as, “I don’t see a man in the corner, but I know that you do. Is it upsetting you?” or “I don’t know when your mother will be here. Let’s go listen to the music while you wait.”

- **Keep in mind that this is a difficult area for all of us.** We all have personal values and beliefs when it comes to truth and reality. Each of us has to find a way to respond that is comfortable for us and is not upsetting for the person with dementia.

Things Not To Do

- **Don't argue with the person.** This always makes the situation worse. It is important to remember that a person with dementia no longer has the ability to be rational or logical to the extent you do.
- **Don't order the person around.** Few of us like to be bossed around and the person with dementia is no exception. Even when your words are not understood, your tone of voice will be.
- **Don't tell people what they *can't* do.** State directions positively instead of negatively. Instead of "You can't go outside now," try "Let's sit down here and look at these pictures."
- **Don't be condescending.** It is hard not to use a condescending tone of voice when you are speaking slowly and in short sentences. However, a condescending tone is likely to provoke anger, even if the words are not understood.
- **Don't ask a lot of direct questions that rely on a good memory.** Often our attempts at being sociable involve asking people questions about themselves. Remember that people with dementia have memory loss and may feel humiliated or angry if you ask questions they can no longer answer. Try rephrasing. For example, instead of "Who is this in the picture?" say "This must be your daughter." This approach allows the person to reply gracefully and noncommittally if he or she is not sure.

- **Don't talk about people in front of them.** It is easy to fall into the habit of talking about individuals right in front of them, when they can no longer communicate well. It is impossible to know how much someone with dementia understands, and this may vary from moment to moment.

When Verbal Communication Fails

- **Try distracting the person.** Sometimes simply diverting his/her attention to other activities – going for a walk, changing the subject, offering a snack, turning on music – may be enough to diffuse an angry or anxious mood. Try again later.
- **Ignore a verbal outburst if you can't think of any positive response.** It is much better to ignore angry or agitated statements than to become angry yourself. You might also try apologizing and letting the subject drop, or changing the emotional tone of the conversation. (e.g., making a positive, cheerful comment instead of an angry reply.) Sometimes the person just needs to be angry, and we need to allow for that.
- **Try other forms of communicating.** There are lots of ways of communicating that don't involve words. Familiar songs, gentle touching or massage, favorite foods, walking together can often demonstrate concern and affection more effectively than words. These modes of communicating can also help soothe a troubled person and take the edge off difficult moments.
- **Learn your own body language.** We communicate with our facial expressions, posture, the tension in our body, the tone of our voice, our eyes, the amount of closeness or distance we choose, and with touch. It is important to be aware of what your own body language may be communicating.

- **Learn the person's body language.** Learning to read others' non-verbal expressions, gestures, and body language can help us better understand what they may be trying to communicate to us.

Communication Change over Time

As a person's dementia progresses, his/her ability to communicate changes. When this happens, it is the responsibility of the rest of us to adapt our own communication style.

The following story illustrates this point.

A Communication Story

by Beth Spencer

When I met Eva, she had been diagnosed with Alzheimer's disease for about 5 years. She had outlived her husband, had no children, and lived alone in a large house in the country. Eva, a former pre-school teacher, had moved north to Michigan from Kentucky during World War II. As a child in Kentucky she had lived on a farm with her 3 brothers and a sister. I learned all this and more from her stories about her childhood. Eva would describe the church, talk about chores on the farm, and about school life as a rural child. She loved to sing "My Old Kentucky Home" and "Jesus Loves Me," and to recite The Lord's Prayer and the 23rd Psalm. Fortunately, I took notes. Although Eva could talk about her childhood and early married life in some detail, she was confused about the present. She would often say, "My memory is playing tricks on me again."

As Eva's illness progressed, many of the details from her childhood stories began to disappear. There were longer periods when she did not talk, and sometimes words came out garbled. I initiated the songs now, and sometimes I asked questions such as, "You grew up in Kentucky, didn't you?" which usually sparked a memory. Gradually she

had paid caregivers introduced into her home and, eventually, 24-hour help.

I took Eva out to lunch every week, which she enjoyed for several years. One day as our food came, she stood up and invited the entire restaurant to pray with us. The next week she got up and joined a family we didn't know and tried to feed their baby. I realized that we had reached a turning point in terms of Eva's awareness of socially appropriate behavior. After that week, when we had lunch we sat in a booth together – Eva on the inside, me on the outside. By this point, I had to initiate almost all of the conversation. Some of her replies did not make sense to me, but I could still respond in some affirming way, such as "That is interesting," or "I didn't know that."

During this period Eva began to have times when she was anxious and upset and trying to find people who were no longer around, such as her husband. One way we found to help her through this was to hold her hand and tell her the stories of her childhood. By talking of the farm, and the school, and especially her brothers and sisters, we were able to help reconnect her to her past and her memories. Often she would smile and relax, nodding her head at the recognizable stories; once in awhile she could add a detail. Sometimes she would join in reciting the 23rd Psalm or singing one of the songs; other times she simply smiled and nodded with us.

Toward the end of Eva's life, she stopped talking. She would still respond to yes/no questions often, but her world had constricted greatly. Sometimes she seemed to be in distress or pain. The stories did not work anymore – they seemed to be too many words for her, or perhaps they no longer evoked the memories. What did still work were reciting the psalms she loved, singing the songs, and mentioning

her brothers and sisters. At the very end, the one thing that appeared to bring her peace was naming her brothers and sisters, almost like a chant. I don't know if she knew who they were, but something about those familiar names brought comfort and relaxation.

We who cared for Eva had to learn to adjust our words and our ways of communicating and to gradually fill in the gaps that opened in her communication.



SLIPSHEET

Session 5: Rethinking our approach to activities of daily living

Anne Robinson and Jayne Yateczak

Interactive Training Strategies

- Discussion questions and powerpoint slides about promoting independence in ADLs and culture change in residential care.
- Video clips of Charles Brown in two different meal situations.
- A series of exercises to teach staff how to assess ability, modify tasks, and design person-centered care plans.

SUGGESTIONS FOR CONDUCTING SESSION 5

Rethinking Our Approach to Activities of Daily Living

The goals of this session are:

- To help staff recognize that Activities of Daily Living (ADLs) are an important part of quality of life.
- To teach staff about the importance of promoting independence in ADLs and the benefits for both individuals with dementia and staff.
- To teach staff how to assess a person's abilities and limitations and to develop strategies for accommodating brain changes, while promoting independence with ADLs.
- To reinforce the concept that direct care staff play a valuable role on the care team; that their observations are important information that should be shared with the entire team.

This training session is built around a series of exercises designed to teach staff the skills outlined in the goals. Because we feel this is so important, we have provided a background section for the trainer that discusses the philosophy behind this approach and some of the pioneering work in this field. We strongly recommend that the material in Sessions 1 and 2 be covered thoroughly before introducing this session.

This *Suggestions* section includes the following:

- A New Approach to ADLs: Background and Philosophy
- Daily Life in a 24-Hour Care Setting
- How You and Your Team Can Begin to Individualize Care

- Using the Outline
- Innovative Resources and Programs

A New Approach to ADLs: Background and Philosophy

ADLs consist of dressing, bathing, grooming, toileting, mobility, and eating. These activities are a significant part of daily life for all of us. "These [ADLs] are people's most individual and private pursuits. Through them, individuals exert control over their persons, personal space, and property and define their own particular style." (Beck, Zgola, and Shue, 2000, p.47) Each one of us performs ADLs in his or her own unique style. This may include such things as the order in which we do these tasks in the morning, the kind of soap we use or the type of clothes we choose to wear. We all have established routines and preferences for when and how we do these things. ADLs are familiar and meaningful experiences that have been a part of the person's lifestyle for many years. As staff, we need to honor and respect each person's particular style and the significant role these events have played in his or her daily life.

In 1987 the Federal Nursing Home Reform Act of the Omnibus Budget Reconciliation Act (OBRA '87) was passed. This was a landmark piece of legislation that marked the beginning of a widespread movement to reduce the use of both physical and chemical restraints in nursing homes. New models of dementia care are evolving. The focus is now on developing individualized, person-centered care that recognizes each individual as unique, responds to the specific needs of each person, and uses tailored approaches. Creating as normal a life as possible while maintaining functioning and autonomy are viewed as important goals in dementia care.

Many research studies, demonstration projects, and practice guidelines have been developed since OBRA '87. Repeatedly these have emphasized the importance of

finding new ways to increase independence and functioning in people with dementia. Some of the research has been able to demonstrate improved functioning. Many of these studies and articles are cited in the reference list at the end of this section. Several are highlighted below:

- Christian Andersen, et al., (2004), a team from Denmark, demonstrated that quality of life in individuals with dementia is highly correlated with level of independence in performing ADLs.
- Cornelia Beck, Jitka Zgola, and Valorie Shue (2000) have written an excellent article, summarizing the research that has been done in this area. They challenge us to reexamine our approach to programming by suggesting that ADLs should be viewed as an integral part of programming, not something to rush through in order to get to organized group activities.
- Joan C. Rogers and colleagues at the University of Pittsburgh (Rogers, et al., 1999) demonstrated the effectiveness of a behavioral intervention for improving ADL morning care performance among nursing home residents with dementia. Working with significantly impaired residents, they were able to demonstrate that, “Functional gains were evidenced in both resident and caregiver performance. Residents exhibited increased independence in performing dressing subtasks, increased participation in assisted dressing, a decreased incidence of disruptive behaviors, and an increased incidence of appropriate requests for help with ADL.” (p. 1055)
- Carly Hellen, in *Activity-Focused Care*, (1998) has devoted an entire book to the idea that “Activity-focused care involves practical, often simple, innovative care approaches that do not demean, humiliate, or infantilize

persons with dementia. If all life is an activity of being and doing, than all of life requires a commitment to provide or be provided with purposeful and meaningful opportunities.” (p. xvii)

- Cornelia Beck et al. (1997) also demonstrated that independence in dressing could be significantly improved in nursing home residents with dementia when nursing assistants were trained to use prompting techniques instead of doing everything for residents.
- The American Psychiatric Association practice guideline for the treatment of persons with AD and related dementias, states that treatment goals include improving quality of life and maximizing independence of function. “Whatever the intervention, it is critical to match the demand on the patient with his/her current capacities, avoiding both infantilization and frustration, to modify the environment insofar as possible to compensate for deficits and capitalize on the patient's strengths.” (American Psychiatric Association, p. 15)

During these same years since the advent of OBRA, there has been an enormous increase in other housing options for individuals with dementia. The assisted living industry has boomed, creating alternative models of care, sometimes unhampered by regulation. In some instances, assisted living programs have successfully created homelike settings free of some of the rigidity seen in more traditional institutions and a 24-hour cycle of care where ongoing training of staff is viewed as high priority.

At the same time there are many examples of programs that have created lavish physical environments but where little has been done to adapt approaches to care to respond to the changing needs of the individuals living in those environments.

The needs of families go largely unmet. In some instances, the lack of regulation or oversight has led to untrained staff dispensing medications, settings that claim to be specialized dementia programs but include no training on dementia, and other troublesome issues. Some assisted living programs look different, but have the same kind of institutional rigidity that is found in traditional nursing homes. The “key elements” of quality dementia care, outlined by the Alzheimer’s Association are missing (Alzheimer’s Association, 1997).

The research studies cited earlier all highlight the importance of maintaining independence in functioning. If this becomes a primary goal of care, then it is clear that individualized care must become a priority. Let’s look at how care occurs in many 24-hour care settings and the impact on residents and staff.

Daily Life in a 24-Hour Care Setting

When the care and/or behaviors of a person with dementia become overwhelming for the family, the person with dementia often moves to a 24-hour care setting.

Declining performance of ADLs is one factor that often contributes to a move into long term care. In most programs, staff step in and take over the responsibility for ADLs despite the fact that most individuals still could be involved in some part of the process. In an effort to ensure efficient operations, standard schedules tend to be put into place. In many care settings, this means that residents must be up and dressed by a certain time, showers are scheduled on certain days and shifts, and everyone has to be in the dining room at specific times. When this happens, the **goal of maintaining functioning gets lost in a culture of care that is focused on regimented routines and efficiency. The consequences of this approach to care are profound.**

What happens to the staff?

- **Staff become caretakers**, doing everything for the person instead of looking for creative ways to enable each person to be independent. There is a misconception among staff that doing everything for the person means you are providing good care.
- **The care becomes more physically demanding** when we make people more dependent on us.
- **It takes more time** in the long run for staff to lift, move, and bathe people, because of the resistance they encounter.
- **Behaviors such as agitation and combativeness become significant challenges for the staff.** People often become resistant when things are “being done to them.” Addressing these challenging situations requires a lot of emotional energy and time from staff.
- **The time constraints coupled with inflexible routines create a very stressful work situation** for staff.

What happens to a person with dementia in a culture of care that emphasizes efficiency and rigid schedules?

- **People with dementia may resist changing their lifelong routines.**
Example: Mrs. Bell has spent the last seventy years of her life having a bath before going to bed at midnight and strongly resists being asked to change her routine to 6:45 a.m. to accommodate the facility schedule. Most of us would resist this change, but Mrs. Bell is being asked to do it at a time in her life when she is least able to adapt.
- **The person is made more dependent and more functionally impaired** than he or she needs to be, a condition known as **excess disability**. When we do this, we are taking away those skills and abilities which the person has had throughout his or her lifetime. We are

feeding people who, with appropriate cueing and sufficient time, could feed themselves. We dress people when they are still able to do parts of the dressing tasks themselves.

- **The person suffers another loss** – the opportunity to continue to do ADLs in a familiar and independent manner. Thus we deprive him or her of one more familiar, meaningful piece of daily life. Often this is one more loss on top of many other losses: loss of home, spouse, roles, familiar activities, etc. The opportunity to actively participate in things that bring a sense of meaning and purpose to each day may be gone, such as putting in the garden, kitchen or a workshop. And then we take away the opportunity to participate in ADLs.
- **The person's sense of incompetence is increased.** When people are no longer encouraged to do things for themselves, their sense of well-being is affected. They no longer see themselves as autonomous.
- **The ability to creatively express oneself is taken away** when the person is no longer encouraged to make decisions about what to wear or how to style his/her hair. This loss of control over the details of daily life and of one's own body contribute significantly to the depression we see in persons with dementia.
- **The spirit and identity of that person become lost** when we "take care of" or do everything for the individual. We no longer see each individual as unique and special. We lose sight of the person's past and what once mattered for them in daily life. When staff expect the person with dementia to be dependent, it becomes difficult to think about this individual as having potential and having goals in life that in some cases are still attainable.

- When people are dependent on us, it is easy to begin perceiving them as children. After all, much of our time is spent taking care of their personal needs, i.e., dressing, toileting, bathing, and feeding. When we focus on doing everything for the person, it reinforces perceptions that these are children to be taken care of. This tendency to infantilize persons with dementia is very demeaning and humiliating.

Why do we continue to see examples of care that focus on efficiency and the completion of tasks? The classic argument is that it is easier and quicker to do the ADL care oneself. It is easier to do for the person than to focus on identifying and maximizing remaining abilities. Actively involving the person with dementia in the process of ADLs takes emotional energy and skill in knowing which strategies to use to help a person be independent. It also takes more time to develop a personal relationship with the individual and to figure out what parts of the dressing task the person can still do. Frequently one has to offer cues to the person to get them started and then wait patiently for a response. Individualizing care takes time and the entire team needs to be committed to the concept of promoting independence. In many programs the work to be done on each shift is not organized in a way that enables this to happen very well.

How You and Your Team Can Begin to Individualize Care

It is not easy to change long held beliefs about how things have to be done.

Organizational barriers to changing ADL routines from task oriented rituals to a lifestyle where these activities are considered to be an integral part of the day are many layered and complex. Strong organizational and administrative support is needed if these changes are going to be long lasting and successful. The process of change also demands that staff have to be willing to look creatively at the challenges

and to recognize that there is always more than one right approach to solving a problem. We need to be willing to take risks and to explore the questions: Why do we do it this way? How could we do things differently and still achieve the outcomes we want?

We are now seeing more examples of innovative programs that are putting aside the old culture of care and looking at ways to create as normal a life as possible for individuals with dementia. In these programs emphasis is on maintaining the personhood of the individual and providing a daily life that accommodates the person's individual rhythms, routines and preferences. We have given you examples and citations for some innovative 24-hour programs at the end of this section.

The concept of individualizing care and modifying the 24-hour cycle so that it is more responsive to the needs of residents can seem overwhelming and complex. Keep in mind that it doesn't have to be accomplished all at once. **It is a process that may take several years** of patience, perseverance, problem-solving, and working together with other departments to successfully modify routines and practices. It is a process your team of staff need to work through in partnership with the families involved in your program. **It is a process that must be deliberate**, with careful planning each step of the way. The outcomes will naturally follow.

One place to start is by looking at what happens during a typical 24-hour cycle of care:

- Look at each shift separately. Outline the tasks, such as bathing, dressing, meals, etc. that currently happen on each shift.
- Who on the team is primarily responsible for each task? Is individualized, responsive care being achieved?

- What aspects of each shift are working well?
- What aspects of the shift aren't going so well and why?

In your discussions you will probably discover that daily life is still tied to task-oriented schedules that are inflexible and not geared to the needs of persons with dementia. While some structure in dementia care is important, the challenge becomes one of adapting the daily schedule to accommodate as much as possible the individual preferences of people in your program. *Examples:* Can Mr. Campbell get up at 5:00 a.m. and have a continental breakfast? Can Mrs. Bell have a bath before bedtime at 11:30 p.m.? Can Mrs. Gardner stay in bed until 9:30 a.m., have breakfast in her bathrobe before getting bathed and dressed? Can Mrs. Tate putter around in the kitchen at 3:30 a.m., cleaning out the drawers and cupboards?

- **Select one aspect of the schedule you want to change.** Keep in mind that many times these issues involve other departments such as dietary, housekeeping, activities, or the rehab department – they need to be involved in the planning and decision-making about the changes to be made.
- **Begin the process of redesigning** the one aspect of the schedule that you have selected as an interdepartmental group (which should involve staff from all levels, including direct care staff). Many programs have been successful beginning with mealtimes. (See references later in this section for information on changing mealtimes.)

As you go through this process together the ultimate goal is to create a 24-hour cycle of care where ADLs become a primary focus of programming. Getting up, bathing, dressing, and having a pleasant meal with a friend become important events in the day. They determine the timing and pace of each shift. As Jitka Zgola says, "It is

these precious experiences that enhance a person's care and quality of life.”

Powerpoint slides: We've included several slides on the CD that list points adapted from Tom Kitwood's work (Kitwood, T., 1997) on the “old culture” versus the “new culture” of dementia care. It may be helpful to put these up briefly and discuss what this means in terms of the culture of care in your program. The points on the overheads are the following:

Old culture of dementia care:

- medical model
- disease-focused
- dementia viewed as hopeless
- care revolves around institutional schedule
- getting the job done most important goal

New culture of dementia care

- person-centered care
- residents viewed as alive, responsive, relating to each other, leading meaningful lives
- staff focused on creating empowering environments
- respect for unique qualities of each person
- care team committed to ongoing assessment and adaptation
- as normal a life as possible, most important goal

As trainers, mentors, role models, we must:

- help staff see the essential humanity and spirit of the person;
- help staff focus on the person behind the disease;
- teach staff to help each person function at the highest possible level;
- teach staff to focus on strengths;
- help staff understand individual differences.

We need to change the way in which the work gets done:

- look at ways to reorganize routines and practices;

- help staff develop meaningful personal relationships with residents;
- value time spent telling stories, laughing, holding hands, being together;
- help staff learn how to bring out the best in each resident;
- emphasize relationships, not getting the job done.

As trainers and administrators, we need to look at the language we use to describe the role of staff in dementia care. Instead of using words like “taking care of Mrs. Charles” we need to say, “How can we help Mrs. Charles maintain her independence with dressing? How can we set up the task of bathing so that it is consistent and respectful of her lifelong routine and preferences?” With this approach, the emphasis shifts from “doing for” Mrs. Charles to identifying her remaining strengths and looking at strategies for prolonging her independence. More and more staff are being called “**caregivers;**” some people prefer the term “**care partners.**” These are subtle, complex issues that need to be addressed in staff training sessions.

Using the *Outline*

This session outlines a process for helping staff rethink their notions about activities of daily living. We have chosen to focus on three of the ADLs – dressing, bathing, and mealtimes. A series of exercises, case studies, and worksheets take staff through the process, by focusing on **four themes:**

1. Viewing life itself as an activity of being and doing.
2. Promoting independence in activities of daily living.
3. Learning to assess a person's abilities and limitations, making it possible to help him or her with ADLs in ways that encourage independence.
4. Learning problem-solving skills that can help staff take into consideration brain related changes in dementia

including impaired judgment, sequencing problems, impaired language and comprehension, difficulty with initiation, and perceptual problems.

We recommend that you do these exercises in order, and that you schedule several training or inservice sessions for them. It will take several hours to work through them thoroughly. At the end, staff will have a much better understanding of the four themes outlined above. The exercises are:

Staff Attitudes and Promoting Independence

- Discussion questions designed to help staff reflect on their attitudes as caregivers and the impact these can have on the work they do.
- Discussion questions about the importance of promoting independence, and the impact on staff and individuals with dementia when we don't.
- Video clips of Mr. Charles Brown with discussion questions.

Promoting Independence in Dressing

- Exercise: Adapting the Task of Dressing to Accommodate the Abilities of Individuals with Dementia (in three parts). There is a Trainer's Worksheet for this exercise, in addition to the blank form for staff.
- Exercise: Dressing Case Study, which includes development of a Dressing Care Plan that promotes independence. There is a Trainer's Worksheet for the Care Plan, in addition to the blank form.
- Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Getting Dressed.
- Staff Handout: Getting Dressed: Helping a Person with Dementia Be Successful.
- Family Background Sheet: Getting Dressed

Helping Staff Individualize the Activity of Bathing

- Exercise: Bathing Case Study, which includes development of a Bathing Care Plan that individualizes care. There is a Trainer's Worksheet for the Care Plan, in addition to the blank form.
- Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Bathing.
- Staff Handout: General Tips for Assisting Persons with Dementia with Dressing and Bathing.
- Family Background Sheet: Bathing Habits

Helping Staff with the Mealtime Experience

- Staff Handout: Strategies for Creating a Pleasant Mealtime Experience.
- Family Background Sheet: Past Experiences at Mealtime.

Additional Background Readings / Handouts

There are two additional background pieces for Trainers to help with this complicated topic. You may find them helpful as background reading for you, or you may want to use one of them as an additional staff handout.

- **Designing Therapeutic Activity Programmes for People with Dementia.** By Jitka M. Zgola, Occupational Therapist. This background paper was written by one of the experts in the field of programming, activities, and dementia care, specifically for inclusion in this training manual.
- **Caring Sheet #14: Helping with Daily Tasks.** By Shelly E. Weaverdyck, Ph.D. (On the CD.) This handout, written by a neuropsychologist who specializes in dementia care, looks at common causes of difficulty with daily tasks. There are sections on the environment and caregiver interactions with suggestions for ways to assess and address common problems.

Staff Attitudes and Promoting Independence

Staff attitudes may affect their ability to give individualized care that encourages independence. Many of us work in dementia care because we have a strong need to be helpful and to feel needed. While this is an admirable quality, sometimes it gets in the way of helping people be as independent as possible. At times many of us are guilty of taking away independence by doing too much for the individuals we are caring for. At those times, our own needs are getting in the way of providing the best care. We lose sight of the fact that we should be constantly looking for ways to promote activities or treatments that encourage the individual to participate and make decisions. We have included some discussion questions in the Outline that can begin to address these attitudinal issues. **Though attitudes are not easy to change, we can at least begin to raise staff awareness.**

Next are a series of discussion questions designed to begin a discussion about why it is critical to maintain a person's independence in ADLs. The questions are designed to stimulate discussion about what happens when we make persons with dementia dependent on us and how this dependency impacts staff. It is important to take the time to help staff think about the misconceptions they have about dementia and their goals for care. We need to help staff see that they are an important part of the caregiving team and that much can be done to improve the quality of life for individuals with dementia.

- What happens when we make individuals with dementia dependent on us by doing all the steps for them?
- How does this loss of independence affect someone with dementia?
- Why do we put people in wheelchairs when some of them still have the ability to walk? Why do we lift someone who still has the ability to stand?

- Why do we begin to feed someone when he or she has the ability to eat finger foods? Why do we dress people who still have the ability to pull up their pants and button up their blouse or shirt?

In the **Outline**, there are lists of possible answers to each question to help trainers cue the staff during the discussion. The answers to the first question usually include a series of losses. It is important to point out that these are very significant losses that can profoundly affect a person's wellbeing. Optimal care is not about taking care of and doing for people. This way of thinking only creates more dependency – a behavior we call “learned helplessness.”

At this point, review the term procedural memory from Session 2. Staff need to understand that while memory loss is one of the features of dementia, procedural memory is often times preserved well into the course of dementia. As caregivers we need to look for ways to facilitate procedural memory when doing ADLs.

When you extend your hand in a social greeting to someone with advanced dementia, most likely the person will reach out, and shake it. When people do not respond, it can often be attributed to the fact that this is not something very familiar to them, although there are other possible reasons, such as not being able to see your hand. We call this **an overlearned response**. Jayne Yatzak describes a situation where a very cognitively impaired man was sitting on a chair in the hallway of a geropsychiatric unit. Jayne said to him, “Your shoelace is untied.” Because Jayne's cue was familiar, he bent over and successfully tied his shoelace. He had been doing this pattern of movement for many years.

We believe that it is important for staff to understand that when we do things for a person, such as feeding or dressing them, we are taking away these overlearned skills and making people more impaired than they

really are. **Procedural memory can be lost if it is not used.**

What are some of the benefits to the person with dementia when we focus on promoting independence?

Again, we have included a sample list in the *Outline*.

Videotape: At this point, we recommend that you show two vignettes that are included on the **Training Tape** on the DVD. In the *Outline* there are examples given for each discussion question. You might also decide to use the video clips to discuss mealtime procedures.

Video Vignette #1 of Charles Brown

The first vignette shows a direct care staff member feeding Charles Brown in bed. Mr. Brown has advanced dementia; he also has diabetes and other medical problems which make his care complex. Most of the time, Mr. Brown is fed in his bedroom in the nursing home. There are many reasons why this happens, including staffing shortages, a perception by staff that “this is the easiest way to take care of his needs,” and lack of staff training about the brain changes in dementia and lack of strategies for promoting independence at mealtimes. Clearly the staff member is struggling to figure out ways to communicate with Mr. Brown. He still has the ability to comprehend what is going on in the environment around him, but Mr. Brown has great difficulty producing and saying words.

- What are some positive things that this staff member is doing?
- What could the staff person have done differently to make the experience of eating more enjoyable?
- How might you feel if you were the person with dementia in this same situation?

Note to trainers: It is important to make the point here that the staff member agreed to be filmed during the normal course of

her day. She had not had any specialized training, but was eager to learn. Later this staff member was trained about the importance of promoting independence while helping with ADLs, and she learned techniques to use when communicating verbally and non-verbally.

Video Vignette #2 of Charles Brown

The second vignette shows Mr. Brown participating in a Dinner Club that meets weekly. Members of this special mealtime group were chosen by staff because they were at risk for weight loss or they presented behavior challenges in the dining room. Staff were particularly concerned about Mr. Brown’s quality of life and wanted to provide him with an opportunity to interact with others at mealtime. Staff also wanted to learn more about strategies for helping Mr. Brown feed himself. Was this even possible?

- What approaches did the caregiver use to help Mr. Brown be successful with feeding himself?
- Mr. Brown’s physical appearance is different. How does his grooming influence your perceptions about his abilities?
- What other factors might be contributing to Mr. Brown’s ability to feed himself?

Note to trainer: We have observed that grooming and positioning make an enormous difference in two areas – how the individual feels about him or herself, and how staff perceive the person’s abilities. It is helpful to use the contrast in Mr. Brown’s appearance to talk about why grooming is very important to enhancing a person’s sense of self-esteem:

- Ask staff to consider how they might feel if a stranger came to visit when they hadn’t combed their hair or washed their faces.
- Talk about positioning: being in or out of bed, in a wheelchair or in a dining room chair. We see people differently depending on where they are sitting.

- When we make people more dependent on us than they really need to be, what is the impact on staff?
- What are the benefits to staff when the philosophy of care is centered on promoting independence?
- As staff, we face significant challenges and obstacles to shifting our approach to one of promoting independence. What are some of the challenges that interfere with this process?

As you make a list of these challenges and obstacles, it is important to acknowledge the reality of them and to recognize that effective change in any setting requires that these barriers, perceived or real, be addressed by managers and administrators. Clearly direct care staff are the caregivers most closely involved in carrying out individualized care plans. Their perspectives about supports and barriers to providing such care are essential.

Teaching Staff How to Adapt ADLs to Accommodate the Abilities of People with Dementia Promoting Independence in Dressing

The next exercise and case study are designed to help staff think about the adaptations that need to be made to a task based on the person's cognitive and physical limitations. After completing these exercises, staff will have a much better understanding of some of the auditory, visual, and cognitive problems that may interfere with activities of daily living. They will have a repertoire of strategies that can be used to compensate for some of these losses in ability.

You can use the dressing task as the model for addressing issues related to other activities of daily living. We recommend that you take staff through this same process when looking at bathing and eating issues. We have included specific exercises related to bathing and eating.

Exercise: Adapting the Task of Dressing to Accommodate the Abilities of Individuals with Dementia. This will take about forty-five minutes to an hour.

The purpose of this exercise is to get staff thinking about the following:

- Action steps involved in getting dressed.
- Questions to ask about the skill level of the person being helped.
- Modifications to consider for the person with specific cognitive and/or physical limitations.

Note to trainer: You may want to refer to the comprehensive **Trainer Worksheet** in debriefing this exercise. In the Worksheet, we have suggested answers for each piece of this exercise. Staff will not necessarily come up with all of the ideas on the Trainer Worksheet (although they may come up with some that we have not thought of). Much will depend on the experience levels of your staff and whether you do these exercises with staff from different departments and disciplines. In general, the more you are able to do this training with cross-discipline and cross-department teams, the more effective and comprehensive it will be.

Exercise: The Dressing Case Study

This exercise has two parts: Questions 1-3 and Question 4, which is the development of a care plan.

Note to trainers: You will notice in the description that Mrs. Bell puts on a lot of undergarments when getting dressed. Her appearance is very important to her. Frequently staff will suggest that she should wear fewer pieces of clothing because the process of putting on a garter belt, thigh-high hose, and a slip is too complex. It is very important that you make the point that this is a true story. In responding to the wishes of staff, the family purchased a jogging outfit for their mother. Mrs. Bell refused to wear it because this style of dressing was not familiar or comfortable for her. Mrs. Bell

preferred to wear dresses. The challenge became one of modifying the process so that she could continue to successfully dress herself in the manner she was accustomed to.

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Dressing

Hand out and review with staff.

Note to trainers: As you debrief, you may want to refer to the sample care plan for trainers. Discuss Mrs. Bell's desire to be independent and to make decisions about what she is going to wear. Point out the different strategies staff need to be aware of.

We recognize that in many settings, direct care staff are not directly involved in the care planning process. We believe they should be, as they usually know the person best. If this is not possible, direct care staff should be encouraged to share their observations with members of the care planning team. The key questions are designed to help direct care staff structure their ideas so that they can successfully share their observations whoever writes the care plans. It is very important to make the point that a direct care worker is an advocate for the person with dementia and that his/her observations and insights matter to the team.

This exercise ends with discussion about how care plans are created in your setting. There are discussion questions in the *Outline*.

Helping Staff Individualize the Activity of Bathing

Exercise: The Bathing Case Study

This exercise is very similar to the case study and care plan on dressing. It is extremely helpful for staff to work through the bathing one as well, because not everyone is able to carry over the lessons from one activity to another. Also, it is good practice in thinking some more about the issues of autonomy and independence.

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Bathing

Hand out and review with staff.

There is also a **Bathing Case Study** in *Session 7: Teaching Staff Problem-Solving Strategies*, which teaches staff problem-solving strategies for thinking about the causes of challenging behaviors during bathing. The Trainer's Worksheet for that case study provides in-depth analysis of bathing difficulties and strategies for that particular case situation. The emphasis of the exercises in this session is on knowing the person and his or her habits, understanding the individual's abilities and limitations, and learning to adapt and modify care to help the person be as independent as possible. The case study in Session 7 emphasizes identifying as many causes of a problem or difficulty as possible and designing strategies to prevent the problems. Together, these exercises teach staff a variety of skills and strategies for understanding individual needs as they approach the bathing situation.

Helping Staff with the Mealtime Experience

Mealtimes are often a good place to begin the culture change process. The Charles Brown video clips on the DVD, discussed earlier in this session, can be used to begin to examine mealtime practices and raise issues about how meals are served in your program. This video and discussion could be used in conjunction with the staff handout and/or with one of the other resources listed below.

Staff Handout: Strategies for Creating a Pleasant Mealtime Experience

Hand out and review with staff.

There are several innovators in the area of creating more positive and independent mealtime experiences. We recommend the following:

Jitka Zgola and Gilbert Bordillon developed the Bon Appetit! Dining Enhancement Programme aimed at restoring the importance and pleasure of meals in long-term care facilities, especially those serving persons with dementia (Zgola and Bordillon, 2001). A training package is available for purchase. (See *Audio-Visual Resources and List of References.*) Their program is based on the following convictions:

- Meals are the most consistently accessible, manageable and effective health promoting activity we can offer to our residents.
- Failure to eat is the single greatest threat to their physical and emotional health.
- A major part of our normal daily activity is centered around meals, their preparation, serving, sharing and consumption. This preoccupation persists into old age and does not change with disability.
- The meal does not start with the appearance of food on the table and end with the last mouthful. It is far more, including: the preparation of the food; preparation of the dining room; the invitation to the meal, the greetings, conversations and other social aspects of the occasion; taste, color, aroma, presentation and texture of the food; the actual consumption of the food and the dignity and pleasure that is associated with it; termination of the meal, clearing, washing up, and wholesomeness, digestibility, and essential value of the food.
- Meals can be the most significant and meaningful activity of the day, offering experience in sensory and social stimulation, productivity, pleasure and autonomy.
- This is particularly true of residents with dementia, for whom the capacity for familiar, habitual activities and

simple, social interaction is the most consistently retained.

Linda Bump's workbook, *Life Happens in the Kitchen...* (Bump, 2004) is also available for purchase from Action Pact. This in depth workbook is designed to help nursing homes "learn about the innovative dining possibilities that can be options for all types of nursing homes regardless of where they are in the culture change process."

In discussing mealtimes with staff, we generally spend time on the philosophy discussed above and look at the assumptions and beliefs noted below.

Assumptions and beliefs about providing a pleasant mealtime experience:

- Mealtimes are important social and sensory activities in most of our lives. Often we deprive residents in 24-hour care settings of the opportunity to experience pleasant meals. By doing this, we are eliminating one of the most important positive activities from their lives.
- It is important to think about how mealtimes can be resident-centered instead of driven by the schedule of the kitchen. In most settings, the mealtime set-up is based on efficiency for the kitchen and dietary staff, not on strategies that would help residents be more independent in eating.
- Redesigning meal set-ups to make people with dementia more independent in eating is a necessary and worthwhile program goal.
- We believe that even those individuals with advanced dementia retain some social skills and benefit from being part of small social situations. The assumption is often made that they are no longer capable of relating or being part of social situations. When staff believe this, the person with severe cognitive impairment becomes socially isolated, withdraws and is deprived of any meaningful stimulation

- Assessment of people's abilities is as important at mealtimes as during other ADLs.
- To the extent possible, residents should be seated in well designed chairs during mealtimes, rather than wheelchairs and geri-chairs. Positioning in wheelchairs and geri-chairs often makes it impossible for residents to be independent. If some individuals must be in wheelchairs, then attention to proper positioning is imperative.
- We strongly believe that people with cognitive impairments should be encouraged to walk into the dining room, if they are able, or transfer into regular chairs once they arrive.
- Having staff seated with residents at the table helps preserve social function and decrease the barriers between staff and residents. When staff sit down and eat at the table with residents, it is a beautiful opportunity for them to model or show the person what to do. Modeling is one of the most effective ways of reminding people with cognitive impairments about appropriate behavior at the table.

Innovative Resources and Programs

On a national level, there are many groups and individuals working on the idea of culture change in long term care. A few of these are:

Eden Alternative and Green House Movement

www.edenalt.org

www.ncbcapitalimpact.org

The Pioneer Network

www.PioneerNetwork.net

www.PioneerExchange.org

Action Pact Inc.

www.culturechangenow.com

Materials on the CD for this session

Caring Sheet #14: Helping with Daily Tasks by Shelly E. Weaverdyck

Exercise: Adapting the Task of Dressing to Accommodate the Abilities of Individuals with Dementia

Trainer Worksheet: Adapting the Task of Dressing to Accommodate the Abilities of Individuals with Dementia

Dressing Case Study

Dressing Care Plan

Trainer Worksheet: Dressing Care Plan

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Getting Dressed

Staff Handout: Getting Dressed: Helping a Person with Dementia Be Successful

Family Background Sheet: Getting Dressed

Bathing Case Study

Bathing Care Plan

Trainer Worksheet: Bathing Care Plan

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Bathing

Staff Handout: General Tips for Assisting Persons with Dementia with Dressing and Bathing

Family Background Sheet: Bathing Habits

Staff Handout: Strategies for Creating a Pleasant Mealtime Experience

Family Background Sheet: Past Experiences at Mealtime

SESSION 5

OUTLINE FOR TRAINERS

Rethinking Our Approach to Activities of Daily Living

Introduction

- When we help individuals with dementia with activities of daily living (ADLs), we often rush through them to meet our program or institutional schedules. We rush many residents through the parts of their day that they could most enjoy. How many of you enjoy your bath or shower? Enjoy your meals? Enjoy the chance to pick out your clothes and wear what you like to wear?
- We want to have a discussion about the importance of helping the people we work with be as independent as possible.

How our attitudes may affect the care we give.

- Many of us work in the human services because we have a strong need to be helpful and to feel needed. This is an admirable attitude. But sometimes it gets in the way of helping people be as independent as possible.
- At times many of us are guilty of taking away independence by doing too much for the individuals we are caring for. At those times, our own needs are getting in the way of providing the best care.
- We lose sight of the fact that we should be constantly looking for ways to promote and encourage the individual to participate and make decisions.

As staff we all need to reflect sometimes on why we are involved in caregiving.

- **Motivation:** What motivates us, as staff, to care for individuals who are frail and vulnerable? Why do you do this work?
- **Personal need:** How do our own needs affect the quality of our work and the approaches we use when providing care?
- **Personal change:** How willing are we to change our attitudes, if need be, so that our approach to care is one of empowering the person with dementia and promoting independence?
- **What happens when we make individuals with dementia dependent on us by doing all the steps for them? What are some of the losses the person with dementia experiences when we do things for him or her? Example:** Sometimes we lift people who still have the ability to stand. Sometime we end up feeding people who could feed themselves if given the right circumstances.)

Note to trainer: Write staff comments on newsprint. This is not a comprehensive list.

- Loss of self-esteem
- Loss of dignity
- Loss of individuality
- Possibility of becoming depressed
- Loss of self-control or mastery over your life
- Loss of self-expression
- Loss of self-confidence
- Loss of motivation
- Loss of feeling competent
- Loss of lifelong routines
- Loss of spirit and identity
- Loss of feeling like an adult; may feel that being treated as a child
- Loss of the ability to recall familiar patterns of movement (procedural memory) related to activities of daily living

Trainer summary: We have identified a series of losses that people suffer when we take their independence away from them.

These can be very serious losses that affect a person's sense of wellbeing. The best care is not 'taking care of' and 'doing for' people. This only creates **learned helplessness** – where we teach people to be helpless. The best care helps people do as much for themselves as possible, while being aware of their limitations so assistance is given as needed.

Define procedural memory:

Procedural memory is "...remembering how. It is the most basic memory system. It is the process by which we acquire habits and learn skills that we eventually do automatically." (Bowlby, 1993)

Examples:

- Brushing your teeth or hair, setting the table, drying the dishes. These are all things we all do automatically.
- When you extend your hand in a social greeting to someone with advanced dementia, most likely the person will reach out, and shake it. (When people do not respond, it can often be attributed to the fact that this is not something very familiar to them, although there are other possible reasons, such as not being able to see your hand.)
- When you first learn skills, such as riding a bike or driving a stick shift, it is not easy because these are complex processes. You have to think about it each time until a motor pattern is learned and established in your brain. Eventually you don't have to think about it – it becomes automatic.
- Dressing, eating, and bathing are skills that include a lot of **overlearned responses**, which is another term for procedural memory.

Example: A very cognitively impaired man was sitting on a chair in the hallway when a staff member said to him, "Your shoe lace is untied." Because her cue was familiar, he bent over and competently tied his shoe lace. He was successful because he has been doing this pattern of movement for many years.

Procedural memory is stored in a different part of the brain from other kinds of memory. It is thought that the part of the brain where procedural memory is stored is usually spared until the advanced stages of dementia. **Procedural memory can be lost if it is not used.**

What are some of the benefits to the person with dementia when we focus on promoting independence?

The list you make with staff might include:

- **Physical benefits** that may be maintained:
 - Strength
 - Range of motion
 - Balance
 - Coordination
 - Body awareness
- **Emotional/psychological benefits:**
 - Ability to have some sense of control over one's life
 - Improved self esteem
 - Feeling like a competent adult
 - Increased satisfaction with self-care tasks
- **Cognitive benefits:**
 - Helps to maintain procedural memory
 - Helps to keep the person oriented as to what is going on
 - Ability to communicate and interact with others is maintained
 - Improvements in functional abilities. Several research studies have shown the when persons with dementia are given the opportunity to practice ADLs with staff specially trained to prompt and assist effectively, their functional ability improves.

ADL Videos on Training Tape: Promoting Independence in ADLs

Video Vignette #1 of Charles Brown

The first vignette shows a direct care staff member feeding Charles Brown in bed. Mr. Brown has advanced dementia; he also has diabetes and other medical problems which make his care complex. Most of the time, Mr. Brown is fed in his bedroom in the nursing home. There are many reasons why this happens, including staffing shortages, a perception by staff that “this is the easiest way to take care of his needs,” and lack of staff training about the brain changes in dementia and lack of strategies for promoting independence at mealtimes. Clearly the staff member is struggling to figure out ways to communicate with Mr. Brown. He still has the ability to comprehend what is going on in the environment around him, but Mr. Brown has great difficulty producing and saying words.

- What are some positive things that this staff member is doing?
- What could the staff person have done differently to make the experience of eating more enjoyable?
- How might you feel if you were the person with dementia in this same situation?

Note to trainers: It is important to make the point here that the staff member agreed to be filmed during the normal course of her day. She had not had any specialized training, but was eager to learn. Later this staff member was trained about the importance of promoting independence while helping with ADLs, and she learned techniques to use when communicating verbally and non-verbally.

Video Vignette #2 of Charles Brown

The second vignette shows Mr. Brown participating in a Dinner Club that meets weekly. Members of this special mealtime group were chosen by staff because they were at risk for weight loss or presented

behavior challenges in the dining room. Staff were particularly concerned about Mr. Brown’s quality of life and wanted to provide him with an opportunity to interact with others at mealtime. Staff also wanted to learn more about strategies for helping Mr. Brown feed himself. Was this even possible?

- What approaches did the caregiver use to help Mr. Brown be successful with feeding himself? *Examples:* She spoke to him, gave him a lot of time, told him what he was eating, got him started with the spoon, encouraged him, sat beside him.
- Mr. Brown’s physical appearance is different. How does his grooming influence your perceptions about his abilities? *Examples:* Mr. Brown looks more capable because he is dressed in street clothes, not in bed, sitting at a table, well groomed.
- What other factors might be contributing to Mr. Brown’s ability to feed himself? *Examples:* Use of the plate guard, food served in courses, no tray.

Note to trainer: We have observed that grooming and positioning make an enormous difference in two areas – how the individual feels about him or herself, and how staff perceive the person’s abilities. It is helpful to use the contrast in Mr. Brown’s appearance to talk about why grooming is very important to enhancing a person’s sense of self-esteem:

- How would you feel if a stranger came to visit when you hadn’t combed your hair or washed your face?
- We see people differently depending on where they are sitting. How does Mr. Brown look different in the bed and at the table? Would you feel differently about yourself eating in these two situations?

- **What is the impact on us, as staff members,** when we make people more dependent on us than they really need to be?

Some possible responses:

Time: It takes more time to do the care for each person because you have to sit and feed or dress someone one-on-one.

Physical demands: Physically the care is more demanding; it takes much more work to lift and transfer someone, to change a person's briefs because of incontinence.

Behavior issues: Behavior problems related to personal care tend to occur more frequently when the person is not actively involved in the process. **Why might this happen?**

Psychological issues: Staff may feel burdened because of the intensity of the care.

- **What are the benefits to staff** when the philosophy of care is centered on promoting independence?

Some possible responses:

Frees staff: When someone is actively involved in the process of ADLs, it frees up staff to do something else.

In the long run, saves time. Example: If you set up a meal properly and assist the person with getting started, then you can move onto the next person and assist them. One staff person could be assisting 2-3 individuals at one time at a table. If you are able to get someone started with putting on their blouse/shirt and buttoning it up, the caregiver could get started on making the bed and tidying up the room.

Physical care: The physical care at least for a while is less demanding because individuals are being encouraged to maintain their ability to walk, eat, dress. We know that persons with advanced stage dementia often are still able to ambulate with assistance from staff.

Psychological benefit: Staff are more committed and satisfied with their work because they are observing positive outcomes such as a decrease in resistance to care and improved mood.

Control: Staff have more control over how they accomplish the work that needs to be done.

Relief: For most staff there is a sense of relief when they can organize their own work and do not have to conform to such a rigid schedule.

Relationship: When staff have time to get to know the person with dementia, a rapport and a sense of trust can develop, which ultimately make it easier for the staff person to provide care. The person with dementia also benefits from this relationship because he or she is not having to adapt to a stranger who is not familiar with routines and preferences.

There are significant challenges and obstacles we face in shifting our approach to one of promoting independence. **What are some of the challenges that interfere with this process?**

Note to trainer: It is important not to get defensive in this process. Don't forget to acknowledge the reality of some of the obstacles that are identified by staff.

- Lack of understanding about Alzheimer's disease and related conditions, their progression, and the possibilities for intervention;
- Insufficient time to perform responsibilities;
- Absence of a team approach;
- Poor staff attitudes with some staff resistant to change;
- Inflexibility of routines and processes;
- Lack of staff training or role modeling of care alternatives;
- Limited participation of direct care staff in care planning;

- Inadequate staffing;
- Administrative team is not actively involved in the process of shifting from the more medicalized approach to a person-centered philosophy of care that is customized to meet the preferences and needs of each individual;
- Poor communication among staff and different shifts;
- Lack of information about each person's ADL preferences and habits;
- Lack of permanent staffing assignments.

Trainer: Use the powerpoint slides on the CD to summarize this discussion:
 Old Culture of Dementia Care;
 New Culture of Dementia Care;
 As Trainers, Mentors, Role Models...;
 We Need to Change...

Promoting Independence in Dressing

Exercise: Adapting the Task of Dressing to Accommodate the Abilities of Individuals with Dementia.

Note to Trainer: You may want to refer to the comprehensive **Trainer Worksheet (on the CD)** in debriefing this exercise. In the Worksheet, we have suggested answers for each piece of this exercise.

Instructions:

The purpose of this exercise is to get staff thinking about the following:

- Action steps involved in getting dressed.
- Questions to ask themselves about the skill level of the resident.
- Modifications a staff member would make to address a person's specific cognitive and/or physical limitations.

Question #1:

- Hand out question #1 to each person.
- Divide your staff into small working groups of three to five.

- Read the instructions aloud.
- Give examples of action steps involved in putting on a blouse to get staff started.
- Allow about ten minutes for this part of the exercise.
- Debrief together as a whole group.

Question #2:

- Hand out question #2.
- Read the instructions aloud.
- Assign each group one category – Sensory, Cognitive, or Motor Skills.
- Allow ten minutes for this part of the exercise.
- Debrief together as a whole group.

Note to trainer: Point out to staff that they can learn to have a list of key questions in mind whenever they are helping a person with ADLs.

Question #3:

- Hand out question #3.
- Assign each group one of the individuals with a particular limitation.
- Give each group a piece newsprint and marker to write down the customized modifications and/or approaches they would make when assisting the individual with dressing.
- Allow ten minutes for this part of the exercise.
- Debrief each scenario as a whole group.

Note to trainer: It is important to thoroughly discuss the adaptations staff would make, modeling, as much as possible, the approaches. Give staff specific examples and words to use when providing assistance. For example, when getting Miss Brown's attention, staff could say to her, "Miss Brown, look at me."

Exercise: The Dressing Case Study

This exercise has two parts: Questions 1-3 and Question 4, which is the development of a care plan.

Questions #1-3

- Hand out the case study of Mrs. Bell.
- Read it aloud together. Be sure to tell staff that the case study is based on a real person in a real situation.
- Instruct staff to work together in small groups to answer questions #1-3, listed at the end of the case study. Ask them to write answers down on a sheet of paper.
- Allow fifteen minutes to complete this part of the exercise.
- Debrief the questions as a whole group.

Note to trainers: You will notice in the description that Mrs. Bell puts on a lot of undergarments when getting dressed. Her appearance is very important to her. Frequently staff will suggest that she should wear fewer pieces of clothing because the process of putting on a garter belt, thigh high hose, and a slip is too complex. It is very important that you make the point that this is a true story. In responding to the wishes of staff, the family purchased a jogging outfit for their mother. Mrs. Bell refused to wear it because this style of dressing was not familiar to her. Mrs. Bell preferred to wear dresses. The challenge became one of modifying the process so that she could continue to successfully dress herself in the manner she was accustomed to.

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Dressing

- Hand out and review with staff. These are important questions that staff members should learn to ask about each resident they are caring for.

Question #4

- Instruct staff to work in small groups on question #4.
- Ask staff to think carefully about the language they use when writing Mrs. Bell's Dressing Care Plan, based on what they know about her.

- Allow fifteen minutes to complete this part of the exercise.
- Debrief the care plan as a whole group.

Note to trainers: As you debrief, you may want to refer to the sample care plan for trainers. Discuss Mrs. Bell's desire to be independent and to make decisions about what she is going to wear. Point out the different strategies staff need to be aware of.

- How are care plans constructed in our program?
- Do direct care staff have input? If not, how can their valuable observations be included?
- How is this sample care plan different from what would typically be done in your program?

Helping Staff Individualize the Activity of Bathing

Exercise: The Bathing Case Study

This exercise is very similar to the case study and care plan on dressing. It is extremely helpful for staff to work through the bathing one as well, because not everyone is able to carry over the lessons from one activity to another. Also, it is good practice in thinking some more about the issues of autonomy and independence.

***Note to Trainer:** This is a very individualized care plan, based on an actual person. Obviously each care plan developed as part of a person-centered, care planning process will be very individual in nature. What works for Mrs. Kendall may not be the right approach for another resident. We have given you this example, to help you and your staff think about what a truly individualized care plan looks like.

Questions #1-5

- Hand out the case study of Mrs. Kendall.
- Read it aloud together. Be sure to tell staff that the case study is based on a real person in a real situation.

- Instruct staff to work together in small groups to answer questions #1-5, listed at the end of the case study. Ask them to write answers down on a sheet of paper.
- Allow fifteen minutes to complete this part of the exercise.
- Debrief questions #1-5 all together.

Question #6

- Instruct staff to work in small groups on question #6.
- Ask staff to think carefully about the language they use when writing Mrs. Kendall's Bathing Care Plan, based on what they know about her.
- Allow fifteen minutes to complete this part of the exercise.
- Debrief the care plan as a whole group.
- How are care plans constructed in our program?
- Do direct care staff have input? If not, how can their valuable observations be included?
- How is this sample care plan different from what would typically be done in your program?

Staff Handout: Key Questions to Consider when Assisting a Person with Dementia with Bathing

- Hand out and review with staff. These are important questions that staff members should learn to ask about each resident they are caring for.

Helping Staff with the Mealtime Experience

Now we are going to think about the mealtime experiences of our residents. First let's think about some of our ideas and beliefs about mealtimes.

Trainer: Read each of these aloud to staff and allow time for a little discussion before moving on to the next.

- Do you agree with each statement? If not, why not?

Assumptions and beliefs about providing a pleasant mealtime experience:

- Mealtimes are important social and sensory activities in most of our lives. Often we deprive residents in 24-hour care settings of the opportunity to experience pleasant meals. By doing this, we are eliminating one of the most important positive activities from their lives.
- It is important to think about how mealtimes can be resident-centered instead of driven by the schedule of the kitchen. In most settings, the mealtime set-up is based on efficiency for the kitchen and dietary staff, not on strategies that would help residents be more independent in eating.
- Redesigning meal set-ups to make people with dementia more independent in eating is a necessary and worthwhile program goal.
- Even those individuals with advanced dementia retain some social skills and benefit from being part of small social situations. The assumption is often made that they are no longer capable of relating or being part of social situations. When staff believe this, the person with severe cognitive impairment becomes socially isolated, withdraws and is deprived of any meaningful stimulation
- Assessment of people's abilities is as important at mealtimes as during other ADLs.
- To the extent possible, residents should be seated in well designed chairs during mealtimes, rather than wheelchairs and geri-chairs. Positioning in wheelchairs and geri-chairs often makes it impossible for residents to be independent. If some individuals must be in wheelchairs, then attention to proper positioning is imperative.
- People with cognitive impairments should be encouraged to walk into

the dining room, if they are able, or transfer into regular chairs once they arrive.

- Having staff seated with residents at the table helps preserve social function and decrease the barriers between staff and residents. When staff sit down and eat at the table with residents, it is an opportunity for them to model or show the person what to do. Modeling is one of the most effective ways of reminding people with cognitive impairments about appropriate behavior at the table.
- What are the advantages to sitting at the table with residents while they eat?
- How can you help residents be as independent as possible in their eating?
- What could you do differently in your program to make this process work?

Advantages to sitting at the table and eating with residents:

- **Reinforces social skills.** The social graces of many residents are preserved even in advanced stages of dementia. Staff presence at the table can help facilitate conversation and reinforce existing skills. Staff can also help residents be aware of one another, as in the video of Charles Brown. “Staff in the dining room must be the models of appropriate social comportment. Their respectful attention is directed exclusively to the residents whom they are feeding, assisting, or monitoring. People with cognitive impairment need special attention in this regard. Spontaneous interaction is not always easy for them. Therefore, staff may have to initiate conversations among residents.” (Zgola & Bordillon, 2001, pp. 24-25)
- **Assessment opportunities.** While seated at the table with residents, staff can pay close attention to the areas where residents are having trouble, can get a better sense of their abilities,

and can test out interventions, such as those used with Charles Brown in the video.

- **Helps equalize the relationship between residents and staff.** Residents often recognize and are concerned that staff don’t have anything to eat. When staff sit down and eat a snack or have a drink at the table, it is an opportunity for them to be on a more equal footing and to model what to do. Modeling is one of the most effective ways of reminding people with cognitive impairments about appropriate behavior at the table.

Helping residents be as independent as possible in eating:

- **Only give as much help as the person requires.** Don’t step in and do the whole thing for the person.
- **Make finger foods available as needed.** Or offer foods that are simple to eat.
- **Provide only the utensils needed.**
- **Offer foods in courses,** instead of all at once.
- **Know the person’s food preferences.** Many times problems with eating are a result of people being asked to eat things they don’t like or that are unfamiliar.
- **Try having the person do the last step of the task first** (backward chaining). By this we mean, guide the spoon to the person’s mouth and then verbally cue the person to take the spoon out of his or her mouth and to continue eating. This technique is particularly helpful for someone who has trouble initiating a task.
- **Place one hand** under a person’s elbow and the other hand underneath their wrist, to assist with the movement of spoon to mouth. Gently guide the hand to the mouth. Watch to see if the person can take over the

movement and do it on his or her own. Many times a person with cognitive impairment can continue the movement independently. Always be sensitive to the person's comfort with touch.

Trainer: Lead a discussion about changes that would have to happen in order for staff to sit at tables with residents and create a more relaxed meal. Is it possible for staff to eat with residents? What are the obstacles to this? What are the advantages?

Distribute Staff Handout: Strategies for Creating a Pleasant Mealtime Experience.
Review together.

DESIGNING THERAPEUTIC ACTIVITY PROGRAMMES FOR PEOPLE WITH DEMENTIA

By Jitka M. Zgola, O.T.

PROGRAMMING WITH A PURPOSE

I had the opportunity, recently, to present a workshop entitled "Doing Things On Purpose." This title was a particular delight because it reflects two very important aspects of programming for cognitively impaired persons. The first is that the joy of purposeful activity must not be denied even to the most impaired person; and the second is that, as programmers, we have the responsibility to plan activities purposefully so that they respond to the needs, strengths and deficits of individual clients. In order to provide activity in a thoughtful and purposeful manner, we must, first, be able to respond to several questions:

- What is the significance of activity in our everyday lives?
- Is that experience any different for the person with dementia?

Let's start by looking more closely at our cognitively impaired clients. Their situation is very difficult for most people to understand. With no obvious handicap, they are unable to carry out most of the tasks that you and I take for granted. The memory loss, the inability to process information and to plan movements often leaves them feeling helpless, disoriented, and ineffectual. Let's walk for a minute in that person's shoes: Imagine being unable to do.

You have some memory of having done things, pleasurable things, worthwhile things, rewarding things, necessary things, things for which people praised you or thanked you. You still have a lot of energy to do things; but now there is nowhere for you to direct that energy because there is nothing that you can do. When an instrument falls into your hands – a

dish towel, a rake or a pair of scissors, for example – your hands seem to remember what to do with it. At those times it feels good. You get into the rhythm of the job. Your joints and muscles respond and the movement feels terrific! You are making something happen! You are making a difference!

Too many times, though, things do not work well, things end up spoiled. Sometimes people scold you or simply ask you “What did you do that for?” You don’t know. You just know that you were trying to help and somehow things went wrong. At other times someone asks you to do something and you just can’t figure out how to do it. You want to help but you just can’t get things together. Then they think that you’re difficult.

It’s embarrassing. It’s painful; and if it happens often enough, activity becomes something to be avoided. You learn to avoid the pain by just staying out of things. That leaves you in a limbo of inactivity, lost, with nothing to do, no significant social role, causing nothing, controlling nothing and needed by no one.

The most difficult thing to take, perhaps, is the loss of control over your own things. It started when you could no longer drive the car or maybe when the banking got too difficult. It got worse when someone had to come in to clean the house and do your groceries or when they put your tools away for good or when you sat in your kitchen, drinking tea that someone else had made and poured and eating cookies that someone else had baked. You sense that no one is going to praise you again for the baking that they used to love so much.

It will get a lot worse when you have to hand over your dentures for someone else to clean or when they have to dress you and feed you. It will get a lot worse when they give you a child’s puzzle to put together or suggest that you might like to play with

Leggos. Deep inside you know that you are an adult, a responsible, competent taxpayer, no one’s fool. Do they really think you have come to this?

With these things happening to you, how do you feel? Take a few moments to think of a single word that expresses your condition. Do words come to mind like: useless, vulnerable, alone, like a nobody? What do you need? You need something to make you feel useful, safe, as though you belong, as though you have control, like a real person.

Now how can this be accomplished? How do we fulfill our need to feel safe, valued and useful? How do we express our identity or our membership in a group? By engaging successfully in activities. But what kind of activity will serve this purpose for a cognitively impaired person? We must start looking at the concept of activity in a more global and creative way if we are to address the needs that we’ve identified above.

THERAPEUTIC ACTIVITY

When viewed within this context, activity takes on an entirely different meaning from that to which we are accustomed. It is not just a pleasant way to pass the time. It is not just a divergence or an excitement. It becomes an individually tailored therapeutic experience that supports self-esteem and self-concept, determines or established social role, and is a means of maintaining social contact. It must clarify the definition of therapeutic here in terms not of repairing damage or regaining lost skills, but more as a palliative process, a way of making the most of the individual’s abilities and offering him the most comfortable lifestyle. This is a point at which we realize the nature of the responsibility that is involved in planning programmes and the importance of doing so purposefully.

The variety of activities that qualify for this kind of programming is as limitless as the variety of needs, interest and aptitudes of the clients. But to ensure that some very important activity that is basic to any programme is not overlooked, I'd like you to try this exercise 1:

On two separate pieces of paper, imagine yourself making two lists: one of exciting, recreational activities, (skiing, bowling, bingo, arts and crafts, etc; the other of more mundane tasks (dressing and grooming, caring for home and belongings, preparing a snack and sharing it with a friend, looking through the paper, putting, pondering.) Now imagine yourself walking down the street with both lists in your pocket when, before you, appears the Grim Reaper. "My friend," he says, "Your time is up. But I will give you twenty more years if you give me one of these lists. Consider it carefully, though" he cautions. "You will never again be able to do the things on the list that you give me." Which list would you give up?

It is not an easy decision; but it demonstrates the relative value and, therefore, importance of daily living activities in any programme. These are the activities that make a major contribution to an individual's sense of self and sense of control and purpose. These are the needs that we identified at the beginning of this chapter.

Unfortunately these are also the activities that are most easily overlooked in the overall process of providing care. For example: the lady who is roused out of bed and rushed through her a.m. care to get to breakfast in the dining room for 8:00, then spends the rest of the morning in a state of restless agitation or wandering about collecting other residents' belongings, while a hurried staff member makes her bed and tidies her room. If this same lady were able to rise at her normal hour of 9:00, have a continental breakfast in her housecoat and then get herself dressed and washed with

help, she'd probably be happy to putter about making her bed and tidying her room until lunch time. This approach challenges some of our basic notions about long term care, but we already know that the care requirements of persons with dementia in themselves pose a significant challenge to these notions.

Even traditional activity programmes contain elements that suit the cognitively impaired person's needs yet are easily overlooked. Washing dishes, for example, is a necessary chore that is usually done by a volunteer after most social activity programmes are over. In a programme that serves cognitively impaired persons, washing up becomes an essential part of the programme itself. Not only is it a familiar activity to which even a very impaired person is habituated and can perform successfully, the act of washing up also represents ownership of the programme and membership in the "inner circle," that sense of belonging that is so vital to us all and yet is often denied to the person with dementia.

Virtually every encounter with the person offers an opportunity where the individual's needs for inclusion, affection and control can be addressed by participating in activities of one kind or another. As you pass by to remove Mrs. Smith's empty cup, you can just take it away without a word. No harm has been done, but no good has been done either. On the other hand, one can say, "Mrs. Smith, are you done with your coffee cup?" This is an opportunity for Mrs. Smith to express control. "Would you please hand it to me?" This is including Mrs. Smith in a task. "Thank you." This is expressing affection and regard.

Given this perspective on the importance of every-day encounters as opportunities to promote participation in meaningful activity, we start to view programming, not so much as a collection of interesting

activities or as a series of scheduled events, but rather as an attitude, a perspective and a way of interacting that is responsive to the needs, strengths, and deficits of each individual in our care.

PLANNING A PROGRAMME

A programme can be defined in any number of ways. Every facility has its standing repertoire of regular activities and specially planned events that are available to residents. The cognitively intact person can pick and choose among these activities, to suit his needs and abilities. The cognitively impaired person, however, relies upon us not only to make these choices for him but to design activities, opportunities and approaches that accommodate his deficits while promoting his abilities. This is the challenge of activities for cognitively impaired persons.

The task of planning an individualized programme becomes less daunting and more rewarding if it is approached systematically. The first step in the system is to get to know the person, assess his abilities and limitations and obtain some historical and personal information about his nature, both past and present. This will give us some insight into his needs and the purpose of a programme. Maintaining a focus on the objectives of a programme increases the likelihood that it will be effective. Only once this information has been gathered, should we start considering the kinds of activities that will be offered. These too, should be chosen knowledgeably. Finally, the presentation of the activities and contingencies in case of failure should also be planned carefully to ensure success. We can go through each of these steps individually.

ON-GOING ASSESSMENT

An activity worker who will promote appropriate activities and provide an appropriate level of assistance must have a realistic idea of the person's abilities and deficits. Dementia interferes with

a person's memory, attention, insight, perception, praxis functions and higher cognitive functions such as judgment, abstract reasoning, and language. If the programme is to be effective, the worker must remain aware, not only of the person's ability to perform certain tasks, but also of how his intellectual abilities impede or support function. The following observations will be useful:

To evaluate attentional abilities ask: is the person's attention easily aroused and sustained? Does he concentrate or is he easily distracted? Can he attend to a simple task such as reciting the months of the year backwards? How many digits can he repeat forward and backward? Seven and five respectively are within normal range. A person who has deficits in this area may have difficulty remaining with a task, may wander off topic, may not notice and therefore, remember, occurrences. He is likely to need frequent reminders of the goal of his activity and be redirected to the task repeatedly. An environment free of distractions will be essential to this person's success.

To observe the person's memory skills, ask: can the person recall events of the recent past. Test by asking the person to recall three objects immediately upon seeing them and five minutes after they have been shown. Does the person frequently recall events and situations of the distant past? Is there a discrepancy between the patient's account of his life and that given by others? What is the patient's attitude toward his forgetfulness? Is there evidence of confabulation, spontaneous or in response to suggestion only? The person whose immediate recall and short-term memory are impaired will require repeated instruction, reassurances and reorientation. He will find it extremely difficult to learn new things. On the other hand, the person with well-preserved long-term memory is likely to feel more comfortable discussing

events from the past than the here and now. These long-ago memories can be a wonderful commodity to add to any interaction. Open-ended questions and insistence on facts by the worker may produce confabulation and should therefore be avoided.

To observe the person's ability to reason in abstract terms, note whether the person can extract meaning from statements that do not reflect a concrete reality. Can he understand instructions that involve objects that are not immediately present? Test by asking him to interpret in abstract terms a proverb such as, "Rome wasn't built in a day." Also ask him to explain the similarity between two essentially different objects such as a turnip and a cabbage-both vegetables, or a plane and a bicycle-both means of transportation. A person with difficulty in this area will find it difficult to grasp explanations or conceive of future events or consequences. Instructions should be given, or questions asked, with concrete cues available.

Language deficits can be very subtle. Does this person use circumlocution? Does he sometimes use nonexistent words (neologisms) or nearly, but not quite accurate, words (paraphasia) to express his thoughts? Is there a significant discrepancy between the patient's output when he is speaking spontaneously and when he is replying to questions? The former is usually more fluent and expansive while the later may be sparse and labored. Is automatic speech, nursery rhymes, counting, etc., easier than conversational speech? Are emotional utterances and ejaculations preserved when formal speech is defective? Workers will have to make a greater effort to listen for the message behind the words, pay more attention to nonverbal communications of the patient and pay active attention to the context in which the message is delivered. They must avoid temptation to dismiss garbled

language or jargon as evidence that the patient is "totally confused" or to correct the patient who uses the wrong words. Also resist assuming intact language function on the basis of good automatic or spontaneous speech.

Even if the person's speech is totally impaired, it is still necessary to determine whether he can understand what is said to him. Can he point out a specific object when presented with a selection? Can he indicate a response to simple yes-no questions? Can he follow simple orders on request, e.g. pick up an object, clap his hands? Workers will have to minimize dependence on verbal communication and augment their speech with non-verbal cues such as gestures or concrete objects. Also, one must not assume that the person whose speech is impaired is unable to understand what is said around him.

Even though the patient may be able to read written material aloud, he may not understand its' meaning, therefore reliance on written notices or signs for orientation or reminders should be discontinued. Observe whether the person can follow simple written instruction, e.g. "clap your hands."

Visuo-spatial deficits in perception can make some tasks very difficult. The person with deficits in these functions will tend to be insecure and more dysfunctional unless provided with a consistent environment. He is likely to have much difficulty learning his way around; and is liable to become lost. He will function better given simple, multi-sensory instructions. Observe whether the person judges space and direction accurately? Does he seem to know where his body is in relation to objects in the environment? Does he know left and right? Does he lose his way easily?

Praxis functions that permit the integration of the steps that comprise skilled and learned movements are essential

to success. Can the person accurately carry out, on command, previously learned motor acts such as make a fist, make a ring with thumb and little finger? Can the person imitate such actions? Can he complete a complex task that consists of several steps such as fold a letter, place it in an envelope, stamp and seal the envelope? Does he have undue difficulty dressing, get muddled when inserting limbs into clothing or put garment on the wrong way around? A person with deficits in these areas will require step-by-step cues and instructions to complete complex tasks. This person will be much better given simplified tasks that exploit familiar patterns. He is likely to become more flustered as the worker tries to direct him to do things that he does not understand or to explain to him how he has gone wrong when a mistake is made.

Faulty judgment will make a person more prone to embarrassing “faux pas.” This person will need direct and explicit one-step instructions in order to succeed. He will need help to resolve simple problems or mix-ups to avoid catastrophic reactions. Does the person’s behavior suggest a change in his social judgment? To anticipate problems in this area, observe the person’s ability to solve simple problems and anticipate the consequences of an action. To make a further test, ask some situational questions such as “What would you do if there were a fire in your house?”

The combination of dementia and institutionalization has the unfortunate effect of obliterating information about another realm of important information upon which a successful programme must be based. That is the individual’s past his or her accomplishments, failures, habits, values, hopes, fears, roles, strengths and weaknesses. Our challenge is to search for cures. The first source of information of this kind must be the client himself. Even though his account may not be totally accurate, this is the recollection with

which he is living and upon which he is likely to act. The family and friends are also important. If none of these sources is available, we may use libraries and other resources to familiarize ourselves with the times and places he experienced and so, perhaps, reconstruct some of his history.

SETTING OBJECTIVES

Even though we may have an intuition that this is a good or fun or whatever thing to do, our chances of being effective are much enhanced if we identify objectives and then select activities that will support those objectives. We must know what we expect the client to get out of his participation in the activity. Our approach will be different if we know how the activity will support health, what psycho-social needs it is planned to support, or what level of sensory stimulation it is intended to provide. For example, if we wish a person to feel nurtured and pampered, we are likely to do things for him. If on the other hand we aim to make a person feel useful and appreciated, we are better off to ask him to do things for us. If we focus on the aim of enhancing sensory awareness in our very impaired clients, we will remember, as much as possible, to invite them to smell, taste, and feel the ingredients that we use during a cooking session.

SELECTING MEANINGFUL ACTIVITIES

Is there any formula for identifying activities that are most likely to be meaningful to the person with dementia? There are guidelines, five criteria that can help to steer us in the right direction.

Firstly, the activity must be relevant to the individual’s status and self-image. Most important here is that the activity never demean or even seem to demean the person.

Secondly, the activity must be voluntary. This does not mean that we should not try to overcome the person’s reluctance that

stems from fear of the unknown, shyness, or apraxia; but we must never coerce a person into an activity against his will.

Thirdly, the activity must have a purpose that is obvious and acceptable to the participant.

And finally, the activity must offer the person a reasonable chance of success.

Although there are no hard and fast rules, there are certain abilities that are usually spared by dementing illness and that most persons with dementia retain long into their illness. These are the abilities that must be exploited if we are to promote successful participation. They are the ability to:

- Perform over-learned patterns of movement
- Experience pleasurable and unpleasant sensations and emotions; and
- Hold an opinion or offer advice.

There are also some activities whose characteristics make them more likely to succeed with cognitively impaired persons. These are activities that:

- Consist of one or two simple steps that are repeated;
- Are predictable and require no innovation or problem-solving;
- Engage concrete and immediate feedback; and
- Are failure proof.

Examples of such activities are: sweeping and dusting, chopping onions, reminiscing, sanding a block of wood, tossing a tennis ball, winding wool, drying dishes, or painting a clear oil finish onto a piece of woodwork. These activities will meet all the above criteria for most clients. Knowledge of the individual person will provide other ideas, such as knitting, piano playing, serving tea, etc., depending on the person's background and retained abilities.

Novel and innovative activities can be included if they are broken down and presented in sections, each of which meets the criteria we listed above. Crafts, for example can be set up assembly-line fashion where each person can contribute a step based upon his particular abilities, characteristics and needs.

Once an activity has been chosen and the objective for doing the activity has been identified, it must be analyzed step by step. At this point, the activity may be broken down and various parts assigned to different patients. Not only will analysis of the activity give insight into which parts of the task will be suitable to which patients and which parts will have to be done by staff, it will also permit us to determine the extent of each person's participation and the kinds of experiences we expect each patient to derive from the activity. For example, if we are making muffins, one client may be able to chop dates, another may stir the ingredients, and a third pour the batter into the muffin tins. A staff member will have to measure the ingredients while a very impaired person may only be able to watch the activity, taste and smell some of the ingredients and sample the muffins as they come out of the oven. Despite the greatly varying levels of participation, everyone is truly participating. This kind of involvement may come about spontaneously without much planning on the part of the activity programmer. Foresights, however, ensures that it comes out right and that it works each time.

PRESENTING ACTIVITIES

Before an activity is presented, it should be reviewed to ensure that it contains no hidden steps that we might take for granted but that may confound the client. We must remember the resident is dependent on us to save him from failure or embarrassment. Therefore, every precaution to prevent problems must be taken. It is a good idea to rehearse your instructions to see if

they make good sense. Then set up the environment so that it is appropriate to the activity. Have everything available but put out only what you will need for each step. Adherence to the following eight axioms² will help to structure the presentation of an activity in a way that ensures the greatest possibility of success for the cognitively impaired person:

- Use habitual or over-learned skills
- Avoid confrontations
- Eliminate distractions
- Give step-by-step instructions
- Limit choices
- Eliminate ambiguities
- Support instructions with concrete visual cues
- Anticipate and eliminate hazards or potential failures

Once an activity is under way successfully, it is important that the programme worker make sure that it stays on the right track. If you find a set of instructions or an explanation that works—use it consistently! Remember that variety is the bane of the cognitively impaired person while consistency and repetition provide support and comfort and, therefore, promote success!

It is important to know when to correct a client's efforts and when not to interfere. The interruption may destroy his concentration and bring an otherwise enjoyable activity to a premature end. On the other hand, we do have a responsibility to protect the client from danger, embarrassment and failure. Consequently, we should take our cues mainly from the client's response. A person who is having a good time and is pleased with his product should not be interrupted; whereas one who is distressed or perplexed needs help. When help is offered, it should be done as simply and efficiently as possible. Sometimes, it is sufficient to discretely

reposition or replace an object that the person may be misusing. If things go really badly it is best to just stop and start over.

ENGAGING THE “RELUCTANT” RESIDENT

How can one get the reluctant client involved? Don't ask-inform and direct. For example, “We are going to have a game of darts, this way, Mr. Jones.” Give strong concrete cues by showing things you are talking about. Instead of asking an abstract question such as “Would you like some tea?” show the person a cup of tea, while saying, “Here is some tea for you.” The person still has the option of refusing it but is not inhibited by the inability to operate in abstractions. Initiating the activity with the client observing will sometimes help the person overcome inertia and give him a model on which to pattern his actions as he starts the activity. There are certain visual cues that will trigger an automatic reaction. Handing someone a cup of tea will prompt him to take it and drink. Holding up a coat will prompt him to slip his arms in the sleeves and put it on. These automatic reactions are useful tools with which to get the reluctant person involved. Common courtesies are another form of trigger to which most people will respond automatically. For example, asked if she wants to go to a group programme, a lady is likely to say “no.” However, told that the group would love to have her join them, she is much more likely to accept. Most importantly, it is essential that we make sure that the client can do and understands the activity!

COPING WITH FAILURE

The easiest failure to cope with is the one that has been foreseen and, therefore, averted. Nonetheless, in the words of the bard, “The best laid plans of mice and men...” When a project or activity goes wrong, we have, I feel, the ultimate responsibility to remove from the patient

any sense of loss, embarrassment or other negative feeling. In most cases we are dealing with a person who has been coping with failure, compensating and covering up frustration for many years. Our aim is to build self-esteem and promote positive experiences.

Firstly, measure success by the client's reaction only. A person who is satisfied with an effort of which we may be critical is best left alone. A person who is dissatisfied with his work, though, will not be made to feel any better by our efforts to convince him otherwise. In fact, the right to be self-critical and set one's own standards is important and must be respected.

If we have made the error of exposing the person to an activity that reveals a lost skill (I once asked a former school teacher to write her name. She was unable to do it and I was devastated.) We should not deny the gravity of the loss, but rather provide comfort and acknowledge it compassionately.

Whenever it is possible and realistic to do so, deflect or share blame. If the outcome of an activity is uncertain, prepare for potential failure. We can succeed in finding out that it does not work!

SAMPLE PROGRAMS

We have discussed the tremendous variety of activities that can be included in activity programmes planning. Some specialized programmes, however, warrant mentioning. A particularly useful medium for working with cognitively impaired persons who do not participate in the regular programmes available within the facility or community, is the small group. This kind of programme addresses the social isolation that most of these people experience. In the small group with a closed and exclusive membership, the facilitator can promote a safe environment where each member's integrity as a competent, contributing adult is safeguarded and nurtured.

The group can be used for more capable persons where eventually the act as a unit is to complete some planned activity such as a special meal or project. A group for less competent clients can focus merely on conversation and the social niceties that are retained. The more demented clients can participate in a very rudimentary sensory stimulation group where objects are passed around and explored. Simple, familiar objects such as swatches of lace and velvet, springs of spruce, pine cones, sponges, and any other kind of sensorial interesting material. The remarkable experience of most people who have initiated and facilitated small groups such as these is that so many of the participants gradually come out of their shells and exhibit feelings, sentiments and skills that no one would have expected.

CONCLUSION

The process of planning and presenting activity programmes for persons with dementia must take into account the special needs of individuals with impaired capacity for insight, judgment, initiative, memory, language, perception and problem solving. The objective of such a programme is to gain the individual's cooperation and promote his enjoyment in the performing activities that contribute to both his physical and emotional well-being. In the effort of enlisting the person's cooperation, the worker ensures the dignity and humaneness of both client and worker are safeguarded.

Such a programme will provide relationships and activities that are both meaningful and satisfying to the client. The term "relationships" refers to any interpersonal encounter between worker and client; and "activities" refers to anything that is done with, or affected to, the client, be it a bath, a meal or a recreational activity.

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1. American Alzheimer's Association. (1996) *Overview and Section on Activities of Daily Living in Activities for dementia: a resource book*.
 2. American Alzheimer's Association (1997) *Programming in Key elements of dementia care*.
 3. Zgola, Jitka M. (1999) *Care that works: a relationships approach to persons with dementia*, John Hopkins University Press, Baltimore, Maryland.
 4. Zgola, Jitka M. (1987) *Doing things: a guide to programming persons with alzheimer's disease and related disorders*, John Hopkins University Press, Baltimore, Maryland.
 5. Zgola, Jitka M. (1980) *Therapeutic Activity in Dementia care: patient, family and community*, Nancy Mace ed. John Hopkins University Press, Baltimore, Maryland.



SLIPSHEET

Session 6: Understanding and Preventing Challenging Behaviors

Anne Robinson and Beth Spencer

Interactive Training Strategies

- Case Studies. Four case studies with discussion questions. One case study has an in-depth worksheet for trainers.
- Powerpoint slides with discussion questions.

SESSION 6

SUGGESTIONS FOR TRAINERS

Understanding and Preventing Challenging Behaviors

The goals of this session are:

- To teach staff about factors that may increase challenging behaviors in individuals with dementia, so staff can learn to prevent or minimize them.
- To enable staff to identify underlying feelings and needs being expressed behaviorally.
- To teach staff problem-solving skills that will help them approach challenging situations in a creative, thoughtful, and person-centered way.

It is our belief that sometimes behaviors are misunderstood or misinterpreted by staff, and often labeled in ways that create negative attitudes toward the person with dementia. When staff do not understand the many factors that can contribute to challenging behaviors, they can unwittingly contribute to the behaviors.

Teaching staff how to assess underlying causes of behavior challenges and strategies to prevent them can be very empowering for staff and can significantly affect staff morale. Helping them to understand that the behaviors are a reaction to many factors, including brain changes resulting in dementia and that most behaviors are not intentional, allows staff to view individuals with dementia in a more positive light. When staff recognize that behaviors are often an expression of an underlying need or feeling that can no longer be expressed verbally, they are better able to prevent or minimize challenging situations. When they have been taught

problem-solving skills, staff often feel much less helpless and more committed to trying to solve the challenge at hand.

It is also important to acknowledge that some behaviors can be very challenging indeed, and may not have good solutions. However, we never settle for that explanation until all problem-solving strategies have been exhausted. Even then, we believe that it is important for staff to keep trying to understand the causes of the behavior and to attempt new interventions. In most cases, even the most difficult behaviors will pass eventually as the person moves to a new stage of their illness.

This session draws on the work of many professionals in the field of dementia care, including Shelly E. Weaverdyck, our own manual *Understanding Difficult Behaviors* written with Laurie White, the work of David Sheard, Jitka Zgola, Geri Hall and many others who have been thinking about what causes behavioral challenges.

This Suggestions section includes:

- Using the *Outline*
- Case studies
- Teaching about the impact of the environment
- Videotapes on approaches to challenging behaviors

Using the *Outline*

The primary focus of this session is to teach staff what to look for in a situation by giving them specific questions to ask themselves, and to help them learn to interpret what may be happening. Most of the Outline is devoted to an exploration of the factors that most often contribute to challenging behaviors: the environment, the communication approaches of staff, internal needs of the person, reasons related to the person's past history and the task at hand. For each area we have developed a list of questions for staff to keep in mind as they think about what might be causing the behavior.

Suggested training approaches

When we are training, we often use the overheads and simply talk through the five factors. We usually follow that with a case study to teach how to put this approach into practice. Sometimes we use discussion questions in each area to help staff begin to think of underlying reasons for a person's behavior. We have included discussion questions for each of the factors.

In order to be most effective, you will need to include examples from the individuals your staff are working with. As you move through the overheads with the questions for staff to think about, be prepared to use situations that have occurred in your program to illustrate some of the points. You can also ask staff to think of examples. This makes the ideas concrete and practical. Talking about a specific client or resident's behavior makes the questions less abstract and helps them to gather information in a systematic manner. For example, as you think about the impact of the physical environment, think of some of the people who seem to be most affected by noise or glare or other aspects of the environment.

One very effective way to cover the material and teach problem-solving is to begin with the introductory remarks and then **choose a client or resident whose behavior has been challenging for staff.** Ask them to describe this person's behavior and then, as a group, work through the Key Questions and each of the five factors. The group's responses about the person could be written on newsprint. As you do this, you are teaching a process for evaluating a behavioral situation.

It is easy and useful to teach staff to identify **warning signs** that a person with dementia is becoming distressed, has to go to the bathroom, or some other problem. Give one example of a warning sign – e.g., when Mr. Brown needs to go to the bathroom, he fiddles with his waistband. Then

brainstorm together what other warning signs might be. Again, having examples in mind of people they are working with will make this clearer. There are additional training suggestions related to warning signs in Session 7.

Session 7 will outline a problem-solving process that builds on the framework from this session. The case studies discussed below are one way of beginning to build problem-solving skills in staff.

Case Studies

Another effective way to teach this material is to use a case study right at the beginning of the session. Asking staff to work through one of the case studies immediately gets them thinking about how many different things may contribute to behavioral challenges. We have found that they are often much more engaged in the discussion and the outline after having started with a case study.

The case studies are structured so that staff have to identify problems that might be contributing to a particular behavior along with techniques for responding to each problem. Several of the case studies ask other kinds of questions, as well. Included at the end of this session are four case studies. Two more are included in Session 7.

Behavior Case Study 6A:

A Woman Who Resists Bathing

Behavior Case Study 6B:

A Woman Who is Difficult to Understand

Behavior Case Study 6C: An Angry Man

Behavior Case Study 6D: Bathing Concerns

Case Study 6A has a worksheet for the trainer where we have provided sample causes and strategies. We suggest that you begin with Case Study 6A, which focuses on bathing. Bathing is very often an ADL that triggers resistance, and it is an activity that lends itself well to this form of concrete problem-solving. There are several good resources for bathing, which are cited in the

Reference List and Audio-Visual Resources. We recommend Dwyer et al.; Rader's book; and Bathing Without a Battle training package.

We have included another kind of bathing problem in Case Study 6D. The other two case studies involve different issues: a resident who has lost much of her verbal ability and a man who is angry when staff attempt ADLs. Session 7 case studies examine mealtime issues and a woman whose hoarding behaviors and agitation are challenging. Sometimes it is helpful to create your own case studies to address particular challenges that your staff may be struggling with.

Instructions for Case Studies:

- Follow normal case study procedures.
- Give each group a marker and piece of newsprint. Ahead of time, set up two columns on each piece of newsprint - one that says "Possible Causes," the other "Strategies".
- Work through an example with them such as the following:

The Task of Bathing

Possible Causes	Strategies
- Time of day	- Find out when Mrs. Jones preferred to bath and adjust her assigned time.

- Give each group 15-20 minutes to work through their question.
- Debrief the whole group. Mention that there will be some overlap among groups and that that does not matter.

Teaching about the Impact of the Environment

There are several very important issues for staff to understand related to the environment and its impact on behavior:

- **Sensory changes** in vision, hearing, and touch particularly, can affect the ways in which they older people perceive their environment;

- **Brain changes from dementia** (as discussed in Session 2) can affect the ways in which people perceive their environment;
- Individuals with dementia have **less ability to compensate for the changes** from sensory loss than other older adults;
- Individuals with dementia are **much more dependent on the environment for cues** – cues that tell them where a particular room is, what a space is for and how to behave. Some spaces give no cues or conflicting cues. A room that is used for both eating and activities may be confusing to some. An exit sign may be a cue that the person should try to leave.
- **Loud or unidentifiable noises** can be contributing factors for some of the challenging behaviors we see in the people we care for.

It is helpful to review with staff the normal sensory changes that occur with age and to think about what this means for people with dementia. It is very important for staff to know whether those they are caring for have vision or hearing problems that may be contributing to their difficulties.

It is relatively easy to make slides or photographs of different aspects of the physical environment in order to trigger discussion about it with staff. In training we have used slides that show environmental features such as:

- glare or dark shadows on floors that can be misinterpreted for a wet spot or ice;
- complicated floor/carpet patterns that may be misperceived as spots on the floor;
- multi-purpose rooms that are used for different activities during the course of the day, and do not give helpful cues;
- long hallways with many doors with few or no orienting cues.

If you decide to take photographs, be sure you have permission to do so, and that you respect confidentiality issues of staff and clients or residents. When discussing the physical environment, it is important to be concrete and to talk about positive changes that can be made that don't involve a lot of money.

Physical Environment Exercise

On the CD is an exercise to help sensitize staff to the impact of the environment on all of us, but particularly on those individuals with dementia. The Physical Environment Exercise asks staff to analyze different aspects of the physical environment and to think about the possible impact on behaviors of clients or residents. We have used this type of exercise in residential care settings that were able to institute some inexpensive changes to make the environment more supportive for people with dementia. Again, this exercise can be worked on in small groups or by the whole group.

Videotapes / DVDs

There are several videotapes that we have used in training about responding to challenging behaviors. We feel that it is important to preview videos carefully – some of them inadvertently reinforce stereotypes, label people, and focus on behaviors in ways that are not consistent with our philosophy. Ordering information can be found in Audio-Visual Resources.

Video Series: Everybody Wins! Quality Care without Restraints. This is a six videotape series (12-14 minutes each) that includes tapes on several behavior-related issues. The one that we most often use, *Getting Hit, Grabbed, and Threatened: What It Means, What To Do*, is on the DVD with the Training Tapes. This tape, which is set in a fairly traditional-looking nursing home, is one of the best examples of problem-solving and creative staff interventions. The viewer sees very real situations, staff approaches that are not

working, and then staff approaches that have worked. The video is very realistic about situations that occur and the fact that we can't always solve them.

Videos: Bon Appetit! How to Create Meaningful Mealtimes in Long-Term Care. This excellent set of two videotapes examines some of the problems with mealtimes in long term care settings and offers a model approach that is built on a philosophy of person-centered care. Each video is 21 minutes.

Video: Recognizing and Responding to Emotion in Persons with Dementia. This 22 minute video teaches staff how to decipher non-verbal communication in people who have lost some of their verbal skills. The video demonstrates how to understand the feelings that the person with dementia is expressing in various non-verbal ways. We generally use the portion that focuses on non-verbal communication.

Video: Choice and Challenge: Caring for Aggressive Older Adults across Levels of Care. This 22 minute video shows real life examples of older people exhibiting aggressive behaviors and discusses strategies for preventing or diffusing the behaviors. There are several very good vignettes in this videotape.

Bathing without a Battle: Creating a Better Bathing Experience for Persons with Alzheimer's Disease and Related Disorders is a video and CD package that includes person-centered approaches to bathing, information on bathing supplies, training information and ideas for different levels of staff.

Training Package: Creating Successful Dementia Care Settings. This package includes four books on various aspects of dementia care and three videos of different lengths (21 – 40 minutes). The videos address ways to enhance abilities as well as suggestions for minimizing disruptive behaviors.

Materials on the CD for this session:

Staff Handout: Understand and Preventing Challenging Behaviors

Five Factors to Help Understand Behaviors – Key Questions to Ask Yourself

Physical Environment Exercise

Behavior Case Study 6A: A Woman Who Resists Bathing

Worksheet for Case Study 6A

Behavior Case Study 6B: A Woman Who is Difficult to Understand

Behavior Case Study 6C: An Angry Man

Behavior Case Study 6D: Bathing Concerns

SESSION 6: OUTLINE FOR TRAINERS

Understanding and Preventing Challenging Behaviors

Trainer: You may want to begin with Case Study 6A: A Woman Who Resists Bathing.

Introduction

- **Alzheimer's disease and other kinds of dementia immediately make many people think, "difficult behaviors."** This is what we want to get away from.
- **All of us use our behavior to express our feelings and our needs.** For example, when you are annoyed with someone but don't want to tell them directly, how might you behave? You might frown at them, or walk away, or snub them.
- **We have the ability also to use language to express our feelings and needs. People with dementia aren't always able to do that.** Many times it is their behavior that expresses what they feel or need, since they can't say it with words.
- **Brain changes in dementia sometimes cause a person to have emotional reactions and behaviors that are distressing to the person and to staff.** Changes in the brain may account for the person's inability to react the way he or she would have in the past. However, **often there are factors in the environment, in interactions with other people, and in the way in which a task is structured that lead to challenging behaviors.**
- Sometimes we can modify the environment, or our methods of communication, or the task the person is engaged in. **These modifications can reduce or prevent some of the behaviors that are challenging.** It

is important to remember that each person is unique and changes over time and from day to day. Hence, interventions must be adapted to accommodate the needs of the individual at that particular moment in time.

Behaviors are not intentional, but are the result of the disease process.

- Lecturing or scolding the person to make him or her feel guilty is not an effective technique.
- Trying to reason with the person will not work because the changes in the brain have taken away the person's ability to control the expression of these behaviors.
- The person with dementia is rarely capable of intentionally manipulating behavior just to irritate the staff person.

Staff need to become detectives, to look at some of the underlying reasons that may be causing the behavior.

- Trying to modify a behavior without understanding the underlying problems can lead to frustration for both the caregiver and the person with dementia.

Think of the behavior as a symptom of some underlying need or feeling. Look at what the behavior is expressing. The behavior is not the problem itself.

- Behavior is a red flag that the person is feeling distressed in some way and is trying to communicate.
- The person may no longer be able to verbalize her needs or feelings, even though she can still speak.
- Staff need to learn to interpret the meaning of the behavior being expressed.
- Crying out, restlessness or making repetitive sounds may be signals that the person is in distress.

Example: Mrs. Anderson is sitting in a chair in the hallway, bent over to the side. She is wringing and shaking her hands and moaning for many hours at a time. In the old culture of dementia care, she would be labeled “agitated,” and perhaps put on psychotropic medications. In the new culture of dementia care, Mrs. Anderson is viewed as a person who is trying to tell us something with this behavior. We need to figure out what it is: Is she in pain? Does she need to go to the bathroom? Is she exhausted from sitting in one spot too long?

Each of us has a breaking point where we have just had enough and things are out of control. We break down and can’t function very well any more. Before we reach this breaking point we may get more and more anxious or frustrated, then we lose control and explode or sob.

- This loss of control is also what happens to the person with dementia when he or she is overwhelmed and unable to handle stress in the environment. The level of anxiety for the person may become unmanageable, leaving him or her unable to cope. (Hall and Buckwalter, 1987).

- Things that we don't even notice may be overwhelming for a person with dementia.

Example: We walk into a large room full of people talking and moving about and the TV is on. To us this is normal and we have the ability to adapt to the situation. For someone with brain damage, the background noise and excessive movement of people as they mingle with one another may be very frightening and distracting.

- The staff member’s primary goal is to take care of the person’s distress or confusion immediately rather than letting it escalate to more challenging levels.

It is important not to dismiss seemingly irrational or negative behavior.

Example: A person endlessly repeats the motion of beating her hand against the side of the chair. This may be one of the few remaining ways in which someone with late stage dementia can still express him or herself. Pounding on the table or pacing, if carefully observed, will change in intensity or frequency with the person’s feeling of comfort or stress.

At times it may be impossible to figure out what is causing the problem, but it is always important to try. Sometimes there are no effective strategies or solutions that work consistently because of the disease process. These situations can make us feel helpless; we may feel like we have failed.

- Keep in mind that some of these behavioral symptoms will disappear as the disease progresses. However, as the behavior diminishes, the person is becoming more cognitively impaired which can be emotionally very difficult for the caregiver.

Key Questions

- **What is happening?** Describe in detail the behavior or concern. Be very specific in your description about what the person is doing.

Example: “Mr. Bailey struck the staff member’s left arm when the caregiver was changing his brief” rather than “Mr. Bailey was combative during personal care.”

- **Who is affected by the behavior?** Other residents? Other staff? Family members? Visitors? Is the behavior really a problem? Moving a chair back and forth from one place to another in a common area may be an annoying problem for the staff but not for the residents. Is safety a concern?

- **Where does the behavior occur?** In a particular room? Is the room noisy or quiet? Is the room filled with lots of people? Is it a familiar space?
- **When does the behavior usually occur?** Is there a particular time of the day when the problem seems to get worse? How long does the behavior last?
- **What was going on right before the behavior occurred?** Was there something that triggered the behavior?
Example: Was the television on during the meal? Was there too much confusion at change of shift? Were caregivers talking loudly back and forth to each other in the hallway?
- **What feeling is the person with dementia expressing at the time of the behavior?** Anger? Frustration? Sadness? Fear? Confusion?

Warning Signs

Sometimes people with dementia may exhibit clues or warning signs that indicate that they are becoming increasingly upset or have some other kind of need. Learning to identify the signs for each person is important. **If we can identify warning signs, we can often defuse a person's anger or agitation before the behavior gets out of control.**

Discussion question: Can you think of some examples of people you have worked with who have given you a behavioral warning that "a challenging behavior is coming?"

Example: When Mrs. White is becoming frustrated, she often slaps her hand against her thigh. This is a warning sign that she is anxious about something that is going on.

Example: When Mr. Adams has to urinate, he fiddles with his zipper. If someone does not show him how to find the bathroom, he will be incontinent.

Non-verbal warning signs include:

- **Body language:** threatening gestures, clenched fists, reddened face, gritting the teeth, rapid eye movement or refusal to establish eye contact, breathing rapidly, frowning, turning pale or flushing, trembling of hands or body.
- **Changes in the usual pattern of physical activity:** pacing, wringing hands, throwing things, picking at clothing, becoming withdrawn and quiet, crying, restlessness, repetitive hand movements.

Verbal warning signs include:

- **Changes in speech patterns:** raised voice, speaking faster, muttering, swearing, using obscene or threatening language.

Why a Challenging Behavior May Be Occurring: Five Factors

There are many things that can contribute to the occurrence of a challenging behavior. An important part of problem-solving is thinking through the possible reasons in a systematic way.

We will look at five factors that may contribute to behavioral issues: the environment, the staff member's approach, the past history and behaviors of the person with dementia, internal needs of the person, and the task that is being attempted. For each factor we will think about key questions that are helpful to ask.

The Environment

Each of us experiences the environment around us through our senses: our ears, eyes, nose, taste and sense of touch. The environment can significantly affect a person's behavior and level of functioning. There are a number of things that staff should be sensitive to when evaluating how the environment contributes to a person's behavior.

Individuals with dementia are more dependent on their environments than the rest of us for environmental cues about where they are, what they are supposed to do, how they are supposed to behave.

Example: Mr. Ross is standing in the activity/dining room looking confused. As he looks around he sees tables and chairs and a few sleeping residents, but mostly it looks like a big bare room. He may or may not remember that he eats meals here. There is no visual cue, no one to tell him, and no smell to cue him what he is supposed to do in this space right now.

Discussion question: What are some of the things in the physical environment (that is, characteristics of the building or the design) that you have noticed affect people's behaviors and moods?

- **In what room or area of the program did the behavior occur?** Describe the space. How large is the room? Think about the configuration of the furniture in the room. Does it contribute to socialization? Isolation? What types of furniture are there? Does the room look home-like or institutional? Who was in the room when the behavior occurred?
- **Have there been any changes in the layout of the furniture in the room?** Change may be very upsetting. A person with dementia depends on the environment increasingly as the cognitive impairment becomes more severe. The brain's ability to adapt to spatial change is often impaired. (Weaverdyck, 1990).

Example: Staff have decided to move the furniture around to give the room a new look. Mr. Andrews gets angry when he enters the room. Although he cannot articulate why, he doesn't know where his favorite chair has gone and he feels lost.

- **Is the environment unfamiliar?** While bus trips and outings can be fun and are a change of pace, some people with dementia may become confused and unable to cope in new situations. Careful planning needs to be done in order for small group outings to be successful.
- **Is the room too hot or cold?** Remember, older people are very sensitive to changes in temperature. While the temperature may be comfortable to caregivers, older people may feel chilly because of a fan or air conditioner. Resistance to bathing is frequently caused by the bathing area being too cold.
- **Is there adequate light?** Going from a bright to a dark area can cause someone to become anxious or fearful. Shadows may cause problems for walking and may be a contributing factor to delusional behavior.
Example: Late in the afternoon shadows would begin to form on the floor in Mrs. Winn's room. As the wind blew leaves on a tree outside, Mrs. Winn would sometimes become very upset about "bugs crawling on the floor." Caregivers eventually realized that Mrs. Winn wasn't hallucinating; rather the poor lighting in her room late in the afternoon combined with her impaired vision were the reasons for her agitated behavior. Shadows and glare on the floor can be easily misinterpreted as wet spots or indentations.
- **Is there a lot of noise in the room where the problem behavior occurred?** Was the TV too loud? Was the TV program appropriate or was there an intense drama, angry debate or news that might be upsetting or misinterpreted by someone with brain damage? Is there an intercom system? Inappropriate music playing? Noise from a vacuum cleaner and other housekeeping equipment?

Example: Residents in one residential care program became very distracted and anxious each time the noisy ventilation system came on.

- **Is glare or direct sunlight from a window in a room affecting the person's ability to see to perform a task?**

Example: Glare from a white bathtub might cause someone to be fearful of taking a bath because he or she can't see how deep the water is. A colored strip of tape on the side of the tub to mark the water level might help. The contrasting dark color against the light may help the person to see that the water is not very deep.

- **Are there a lot of people in the room?** Large groups can be confusing and upsetting, particularly as people become more cognitively impaired. Many of the behaviors at meal time could be prevented if people were divided into smaller groups based on their personalities, eating abilities, and special needs.
- **What is the emotional environment of the room?** Tense? Peaceful? Overstimulating? Boring? When staff are working short and having a difficult day, the emotional environment for residents can become tense and anxious.
- **Is the behavior related to the weather or specific time of day?** Closing the blinds in a room as it begins to get dark may help to allay some of the concerns someone with dementia might have about where they will be spending the night.
- **Are there meaningful cues to help people find their way?** Are there signs on walls and appliances? Are the signs large enough and in places where they will be noticed? Are the cues large enough to read and are the words understandable?

Example: The international symbol for bathroom is very abstract and may be confusing to someone who is desperately searching for the toilet. Are signs low enough so that a person in a wheelchair can see them?

- **Are there opportunities for privacy?** Even when a person is very impaired, he or she may retain a sense of modesty. Hence it is important that the door to the bedroom or bathroom can be closed and that windows can be covered.

The Staff Member's Approach To Communication

Many times our approach to communicating with the person with dementia is the underlying reason why the interaction did not go well. We may be well-intentioned, but may not understand how the person is interpreting what we say or do.

- **It is easier to change our approach** than to try to change the person with brain damage.
- Being sensitive to how we communicate is one way to reduce the frequency of agitation, anger, or frustration in the person with dementia. As the person's verbal and comprehension abilities become more impaired, staff need to be very skillful in their interactions.
- **The task for staff is to learn the language of dementia.** In some sense, the person with dementia speaks and understands a different language.

Discussion question: Can you think of some examples of times when your approach to a person with dementia may have contributed to problems or difficulties? We have all been guilty of this at times! What did you do or say that may have made the situation worse?

- **How well have I gotten along with this person in the past?** Are my attitudes or feelings about the person affecting the way I behave towards him or

her? Some people with dementia and their caregivers genuinely do not get along and these dynamics need to be addressed.

Example: With the person who is challenging, do I feed the person mechanically and hurry to finish because I am uncomfortable or do I patiently encourage the person to feed him or herself?

- **Has this person been labeled by other caregivers as “a screamer” or a “hitter” or “feeder?”** Is this affecting the way I approach the person? Our own attitudes are a very important part of communication and need to be carefully evaluated.
- **Am I aware of my own verbal and nonverbal behavior around this person?** Were my instructions short and simple? Was I speaking too loudly? Was I being condescending? Do I feel comfortable asking others to observe my style of communication so I can modify my approach?
- **How was I feeling when the behavior occurred?** Tired? Rushed? Impatient? Frustrated?
- **Did my words match the expressions on my face?** Remember, many people with dementia are likely to respond to the feelings being expressed rather than the words.
- **Did I set realistic expectations** about what I should be able to accomplish with the person given his or her impairments?
- **Are there other staff members who have good rapport with the person?** What approaches have they found to be successful? How does this information get shared with the rest of the team?
- **How can we better support one another when we have a difficult assignment?** In some programs, staff have developed a buddy system, working together as a team to relieve

each other. The first staff person goes in and does some of the initial care knowing that the interaction will be difficult. The second person then steps in to relieve the first person and continues with the task to be accomplished.

- **How do I respond and cope in stressful situations?** What have staff found to be helpful? Caring for individuals with dementia can be exceedingly frustrating and fatiguing. (**Trainer:** Discussions about how to manage stress and take care of ourselves are important to maintaining morale and turnover. See Session 9.)

Past History And Behaviors

- **What do we know about the person’s mental health history?** A person with a long history of depression, for example, may be experiencing episodes of depression on top of the dementia that are having a profound effect on behavior.
- **What do we know about this person’s personality?** This gets back to the Core Qualities discussed in Session 3. The more we understand about who this person is and was, the better chance we have of understanding the person’s behavior.
Example: Eva loved people, and especially children, all her life. She was outgoing and sociable. During the middle stages of Alzheimer’s disease, Eva would approach strangers in stores and begin stroking their children, or try to lift them out of the shopping carts. This behavior was frightening to staff, but was very understandable when you knew something about Eva. It required careful thought and planning before taking her into public spaces.
- **Is the behavior a variation on a coping strategy that the person always used?** If possible, check with the family to find out how the person

has coped with frustrating situations and disappointments in life; this information might provide helpful clues about the behavior.

Example: Mr. Smith had a very successful military career for many years. He was a competent and independent man who had strong opinions about things. When he sensed that the caregivers in the nursing home were not being attentive or serious about what they were doing, he became impatient and verbally angry with them. Clearly his career had strongly influenced the way he responded to situations that needed attention.

Example: Mrs. Jones used vigorous exercise to cope with frustration in her earlier life. Now when she is upset she often tries to leave the special care unit. A vigorous walk with a volunteer or family member may still help her relieve stress.

- **Have there been important or tragic life events that might explain the person's behavior?** The classic example of this that many residential care programs have had to address is a resident who was in a concentration camp during World War II and is now traumatized by having a shower. However, there are many other events that might affect the behavior of a person with dementia; a few examples are having moved a great deal, extreme poverty, fame, having been abused, etc.
- **Is there information about the person's past work routines that could explain particular behaviors?**

Example: Mrs. Carrington worked the night shift at an auto company for thirty-one years. When she moved to a nursing home, she would not stay in bed at night and insisted on sleeping during the day. Staff finally learned of her work history and realized that it would probably be impossible to change her sleep patterns.

- **Is there information about the person's past routines at home that could explain particular behaviors?**

Example: Mr. Sturgis walked out the exit door, setting off alarms, each day after lunch. Eventually staff learned that during his long retirement, Mr. Sturgis' habit was to walk down the one-quarter mile driveway every day after lunch to get the mail. Once they understood this, they worked out a mail routine for him after lunch, which stopped the exiting behavior.

- **Are there details about the person's hobbies, early life, family, religion, travel, schooling, that might be useful in understanding or explaining behavior?**

Internal Needs Of The Person

Discussion question: What are some things that might be going on inside the person with dementia – feelings or unmet needs – that may be causing the person to behave in a certain way?

- **Has there been a recent change in medications?** People with dementia are very vulnerable to overmedication and to adverse reactions to drug combinations. Although medications can be helpful in managing some behavioral symptoms, drugs can also produce many side effects such as constipation, dry mouth, impaired balance and in some cases may even increase restlessness, agitation and sleeplessness.
- **Are there changes in the person's vision and hearing?** Many of the challenging behaviors we see in dementia are the result of changes in vision (due to cataracts, glaucoma, or macular degeneration) and hearing. Hence the person with brain damage is not receiving complete information through his or her senses. It is important that glasses are cleaned and hearing aids are used as much as

possible; hearing aids need to be turned on and batteries changed regularly. Hearing problems may also be caused by impacted wax.

- **Is the person hungry?** Sometimes agitated or restless behavior occurs because the person has not had enough to eat. For individuals who walk a lot and have a high metabolism, it is important that caregivers keep careful track of food and liquid intake. Also, some people are used to a different meal schedule or style of eating than what is provided; they may not be eating enough at meals, because it is not their usual routine.
- **Is the person thirsty?** The average adult should drink eight glasses of fluid daily. Staff should encourage fluids every waking hour to reduce the risk of possible urinary tract infections and dehydration up until 6:00 p.m., unless other medical conditions dictate otherwise. Oftentimes thermal mugs containing water sit untouched on bedside tables in residential care facilities because the person with dementia is no longer able to remember to drink or may not be able to locate the container or remember what it looks like.
- **Is the person in pain?** In people with dementia, pain frequently is undiagnosed or untreated. Agitation, calling out, and restlessness may be signs of pain stemming from arthritis, blisters or calluses on the feet, ill-fitting dentures, tooth decay or contractures. Bone fractures and skin breakdown can also be extremely painful. **This is a very important area for staff to assess** particularly if the person with dementia is no longer able to tell you that he or she is in pain.

Example: One person's behavior changed dramatically because of the acute pain she was experiencing. Although she could still produce some

words, she was unable to tell her caregivers that she was in pain; three days later she underwent emergency gall bladder surgery.

- **Is the seating comfortable?** Sometimes people with dementia in residential care settings spend long hours in uncomfortable chairs and wheelchairs that can cause problems such as poor posture, circulatory problems and hip and pelvic displacement.
- **Is the person constipated or impacted?** Look for signs of increased agitation, grimacing, delusions, swollen stomach, poor appetite, or holding one's stomach area. Encourage high fiber foods such as oatmeal, fresh fruits, fruit juices and applesauce, along with plenty of fluids to move the food through the system.
- **Does the person have an infection** such as flu or pneumonia that is causing increased confusion? Sudden, unexplained changes in behavior may be the result of a urinary tract infection (UTI) and should be assessed immediately. Look for signs of agitation, frequent urination, sudden incontinence or foul-smelling urine.
Example: Caregivers in one facility learned that Mrs. Michael's first warning sign of a UTI was sudden weepiness when staff approached her to do ADLs. When this behavior was observed, the staff would begin increasing her fluid intake to prevent or minimize the infection.
- **Are there other health problems** such as thyroid disease, kidney and liver problems, poorly controlled diabetes that may be contributing to the behavior problem?
- **Is the person tired?** People with dementia use a great deal of energy trying to complete everyday living tasks. Bathing, dressing and eating require a lot of physical and cognitive energy and can be fatiguing activities.

As the person becomes more cognitively impaired, it is important that there are opportunities throughout the day to relax and to take naps as needed. Sometimes angry behavior is caused because the person is overtired and is unaware of it.

- **How is the person feeling?** The emotional mood of the person with dementia can have a major impact on behavior. Does the person show symptoms of depression? Is he or she afraid? Signs of depression include loss of appetite, sleeplessness, irritability, and withdrawal. Depression in many cases can be successfully treated with antidepressants. Be aware that if someone is feeling depressed, it may seem like too much effort to take a bath or get dressed. Depression in the person with dementia may be harder to diagnose because of overlap of symptoms. But there is a higher occurrence of depression in people with dementia than in the normal population, and depression may make the dementia appear to be more advanced than it is.

The Task The Person Is Doing

Sometimes challenging situations occur because daily living tasks such as dressing, toileting or bathing have not been carefully structured for the person with dementia. Adaptations need to be made so that the person can successfully participate in some of the steps.

Discussion question: Think of a task that you regularly do with a person with dementia. It might be helping them with bathing, dressing, eating, an activity, etc. What are some of the things related to doing tasks that may be causing difficulty for the person? For example, sometimes we are rushed and go too fast for the person.

- **Is the task too complex or unfamiliar?** Sometimes we ask people with dementia to perform multi-step tasks

that are too difficult for them, although they may seem simple to us. The ability to understand a whole task and to recognize the steps that make up the task resides in the part of the brain that is severely impaired in mid-stage and advanced dementia. People with dementia are easily overwhelmed resulting in withdrawal, resistance, and anxiety.

- **Have I planned ahead how to involve the person to the extent he or she is able?**

Example: Putting on a blouse involves many steps. It is important that the caregiver be thinking about how to adapt the task to accommodate the person's cognitive and physical limitations. Knowing when to step in and help the person when he or she is having difficulty is crucial.

- **Is the routine familiar?** Many of us use the sequence of steps that are familiar to us in our own daily bathing and dressing routines; these may be quite different from the routines of those we are helping. If new steps are introduced or are done differently, the person with dementia may have a lot of difficulty adjusting to the new sequence. In getting a history from the family, it can be very helpful to ask about the person's bathing and dressing routines both in the past and more recently.

Example: Some people dress from the bottom up, others from the top down. Sometimes the order of the steps being used is unfamiliar to the person with memory loss.

- **Are ADL routines for each person consistently followed by all the staff?** The ability of the brain to adapt to change or new ways of doing things is very impaired by dementia.

Example: The staff at breakfast were feeding Mrs. Smith, while the staff on afternoons left her to her own devices at mealtime. The inconsistencies may have been adding to Mrs. Smith's confusion at mealtimes.

- **Does the person enjoy doing the activity?** If not, try to make the activity more appealing. If the person is resistant to bathing, try to make the bathroom warm and inviting. Play soft background music to create a relaxed atmosphere and offer refreshments such as yogurt or ice cream.
- **Is the person being rushed through the activity?** Breaking ADLs down into simple steps can be time-consuming. It is important to give the person with dementia plenty of time to process instructions and to perform each step to the extent that he or she is able. This requires a lot of patience on the part of the caregiver who has many tasks to get done. Staff need to check the pace of their movements and tone. Rushing can often trigger anxiety and frustration. When we rush or force residents through tasks, the negative emotional memory of the experience will probably linger for some time afterwards. Staff will then have to deal with the consequences of the unpleasant interaction.
- **Is there flexibility in the person's day-to-day schedule?** The scheduling of activities of daily living and mealtimes needs to be flexible to accommodate the fluctuating mood and functioning level of the person. The fatigue level and tolerance of each person are important factors to consider when planning an activity.
- **Are the supplies for the activity familiar, ready and within reach?** It is important for staff to plan ahead and to have all the needed items, such as towels, soap and clothing collected ahead of time when giving a bath.

Tools used when giving a bath, such as a wash cloth or sponge, should be familiar to the person.

- **Was the person offered a choice?** Sometimes resistance occurs because people have very few opportunities to make decisions and to exercise choices. While too many choices may be overwhelming for someone with dementia, staff need to carefully think about ways to allow the person to make simple choices when possible.

Example: Holding up two shirts and encouraging a response or asking if the person would prefer pudding or ice cream for dessert.

- **Is there enough structure in the environment?** It is important to have a predictable routine which people can count on throughout the day.

Example: From 7:00 a.m. to noon, the morning routine might include having breakfast, doing ADLs, helping to tidy up the room and participating in a late morning movement group. At the same time, there needs to be some flexibility so that the changing moods of residents can be accommodated. Finding the balance between stimulating activity, rest and long periods of inactivity can be very challenging.

Approaches That Don't Work

- **Getting angry with a person** because you thought the person's behavior was done intentionally to spite you.

Example: Staff in one facility made comments about a resident who had unpredictable mood swings and could become physically aggressive. They said "She tries to bully you into doing things her way" or "She always has to have the last word." (Weaverdyck et al.,1997). With this resident, it was important for the caregiving team to recognize that this behavior was the result of the disease process.

- **Using logic to try to talk the person into something.** Trying to convince the person of a particular point of view will only lead to frustration and failure. Also, confrontation causes the person to be more defensive. As dementia progresses, people lose the ability to think logically.
- **Asking the person to “try harder.”** Most people with dementia try very hard to cooperate and to respond to requests by the caregiver. Sometimes the person may no longer be able to do the routine things that we do every day without thinking about them.

Example: Mrs. Watson was having difficulty walking through the door of her bedroom into the hallway using her walker. Some caregivers reported that she was being “difficult and stubborn;” or “She could walk when she wanted to.” They didn’t realize that because of brain changes, she had difficulty coordinating the movements of her legs and arms. When staff put on classical music and gently encouraged her to “Come to the kitchen for breakfast,” most times she was able to move spontaneously to the beat of the music. Rhythm patterns may help a person with dementia initiate movement. (Chenoweth, 2001).

- **Scolding, mocking or embarrassing the person.** Our primary goal is to preserve the dignity of people and to help them save face as they progressively lose their abilities. Teasing is unacceptable.
- **Being parental or patronizing** when assisting someone with daily living tasks. As people with dementia decline in their functional abilities and tasks are simplified, some caregivers have a tendency to order or boss them around. Not only is this approach humiliating, it can trigger aggressive and angry behavior.

- **Telling a person “No,” or “You are wrong.”** As staff, we sometimes forget how often we correct or respond negatively to the person with dementia. Phrases like “Don’t take your clothes off,” “Leave that alone,” “You can’t go home, this is your home now,” or “No, this is not your room. Get out of there,” are frequently used. The person with dementia is just as likely to have a negative reaction to being corrected as we would.
- **Telling the person “Your husband is dead.”** Years ago, reality orientation was a common practice. For someone with dementia, this approach may be very cruel.

Example: Mrs. White, a resident of a special care unit, used to stand by the window late in the afternoon waiting for her deceased husband to pick her up so they could go home and have dinner together. Instead of confronting her about the reality of her husband being dead for several years, staff had skillfully developed an approach to distract her. They would acknowledge what a loving husband and father he had been. Encouraging Mrs. White to go to her room to look a family photograph album helped her feel more secure and connected to him. After 15-20 minutes, staff were generally able to engage her in an activity.

Helpful Tips in Difficult Situations

- **Early intervention is the key to preventing behaviors from getting out of control.** In responding to a challenging behavior, it is important to know the person well and to know which approaches are going to make the difference. Remember, the goal is to assess and problem solve when a person is becoming upset. Be proactive!

- **If a person begins to get angry or agitated, stop what you are doing.** Reassure the person by saying, “I am not going to hurt you. I am your friend. I am here to help you,” or “I am sorry I upset you.” Use empathy.
- **Stay calm and to be gentle in your manner.** Think carefully about your body language. Trying to defuse someone’s anger is a process that can take a lot of time and patience. Remind yourself that “this person is upset and needs your help.”
- **If the person continues to be resistant, try to divert his or her attention.** Go slowly. You might want to point out a picture on the wall or dresser and talk about it or quietly sing a favorite song together. Talking about something else might help to change the person’s mood.
- **After a few minutes have passed, try again to bring up the next step.** Backing off and then going back to the activity you were doing with the person can be a useful technique.
- **If the person continues to resist, leave and try again later.** Most probably, the person will not remember what happened. Sometimes a different staff member may have more success.
- **Whenever possible, have a minimum number of staff interacting with the person at any one time;** several people can be very threatening. Imagine if you were in a foreign country, not understanding what is happening, and feeling angry and upset. How would you feel if two or three officials were all interacting with you at once?

If the Person is Physically or Verbally Aggressive

- **Try to remain calm and confident.** Think about your body language and how this might be interpreted by the person.

- **Avoid disapproving or angry facial expressions and reactions** to what is being said. Be careful not to stare at the person.
- **Respect the person’s space** so that he or she doesn’t feel crowded or threatened. Position yourself so that you are standing slightly to the side of the person rather than in front. Try to maintain eye contact and speak slowly. Avoid touch. Keep your arms at your side but be prepared to protect yourself.
- **Make sure you can quickly leave and get help if needed.** If you know that this person is apt to get angry, position yourself near the door.
- **Give the person some time to work through his or her anger.** Speak slowly as you gently reassure the person that things will be okay. Remember all of us need time to get over angry or upset feelings.
- **Assess the effect the behavior may be having on other people in the area.** Is anyone at risk of being harmed? Encourage the person who is upset to go to his or her room where it’s quiet.
- **Only use restraints as a last intervention** after everything else has been tried. Trust your instincts.
- **Remember, with some people, the approaches you try sometimes may not succeed.** All you can do is be compassionate and try your best. Don’t take it personally. Remember, the people that you are caring for have brain diseases that affect different areas of the brain and cause behavioral symptoms.
- **After a difficult interaction, take a break.** You will need some time to deal with your feelings. Talk with other staff; don’t let your emotions get bottled up inside.

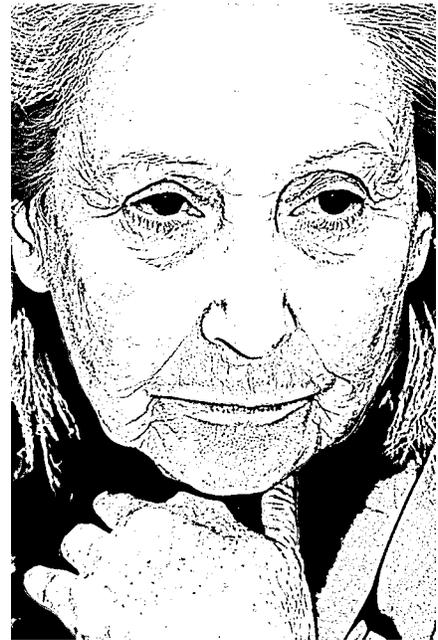
Practicing Problem-Solving Approaches

One of the most important things we staff can learn to do is to become skilled problem-solvers. The more we can learn to approach a behavioral situation as a challenge to be solved, the better able we will be to cope with some of the challenges in our dementia care work.

The first step in problem-solving is to know the people we care for as well as possible – to know about their core qualities, their life histories, the important things about them and their stories that have made them who they are. The better we know a person, the less likely we are to reduce them to stereotypes or labels.

Staff problem-solving sessions are often an ideal way to work out strategies to address a challenging behavior.

Trainer: Use a case study or video here to practice problem-solving.



SLIPSHEET

Session 7: Teaching Staff Effective Problem-Solving Strategies

Roxanne Chang and Jayne Yatzak

Interactive Training Strategies

- Problem-solving process. Outlines a process for problem-solving and development of action plans to address challenging situations or behaviors.
- Exercises. Includes many exercises to help staff better understand themselves and those they care for.
- Case studies. Several in-depth case studies are included to help staff practice problem-solving.

SUGGESTIONS FOR CONDUCTING SESSION 7

Teaching Staff Effective Problem-Solving Strategies

The goals of this session are:

- To teach staff problem-solving skills and a strength-based process that will help them approach challenging situations with residents in a creative, thoughtful, and person-centered way.
- To help staff begin to understand the power of language and the negative impact of stereotypes, assumptions and labeling people with dementia.
- To teach staff how to implement, evaluate, and modify a team-based action plan.
- To provide hands-on opportunities for staff to practice the steps involved in problem-solving and suggestions for implementing the process into facility practices.

Introduction: Why is this important?

This session is designed in two parts. The first part addresses how to train direct care staff about the importance of and the process for effective problem-solving. The second portion of the session is intended to provide guidance and suggestions on how to use this problem-solving process at your own facility for specific individuals with dementia.

Please note that Session 6, *Understanding Why Challenging Behaviors Occur*, lays the groundwork for the problem-solving process. It is very important that you cover that material first.

Behavioral symptoms are common, occurring in 50-100% of people with AD. When an approach doesn't work, staff are required to be able to think quickly and

creatively on their feet to come up with other ideas.

There are few opportunities in most settings for direct care staff to talk about concerns they may have, and often they are excluded from discussion and decision-making about individual residents. Clinical discussions about resident behavior most often occur among professional staff only. Yet, in reality, it is the front-line staff who usually know the residents best. They often have excellent observations and insights about resident behavior. Moreover, many times direct care staff have the knowledge of how to solve problems or address challenging situations, but do not have the opportunity to share these thoughts and ideas with their peers.

Direct care staff deserve and need to be given the tools to respond to the many challenges in caring for people with dementia. Thus, we believe it is very important to teach staff how to work systematically through a series of steps that will lead to the development of a plan or strategy for coping in these situations. A structured process can help staff to identify and solve problems by developing interventions.

Teaching and involving direct care staff in developing interventions for challenging situations when caring and interacting with individuals with dementia will:

- Empower direct care staff;
- Increase staff morale, thereby decreasing staff turnover;
- Encourage team work among them;
- Strengthen relationships between professionals and direct care staff;
- Build relationships between staff and family members; and
- Promote more efficient care and reduce stress of direct care staff.
(Chou (2002); Moyle, Skinner, Rowe, and Gork (2003); Riggs and Rantz (2001).

Using an effective problem-solving approach to create an action plan will also improve quality of life and care for individuals with dementia, by:

- Maximizing strengths and abilities;
- Encouraging constructive, adaptive and pro-social behaviors;
- Limiting the use of physical and chemical restraints;
- Reducing the use of psychotropic medication;
- Improving socialization for individuals with dementia; and
- Strengthening relationships with staff and other residents.

We believe in the importance of scheduling regular problem-solving meetings with staff. However, a foundation must be in place before you begin, which includes:

- Recognition that direct care staff have the ability and knowledge to participate in problem-solving and the development of an action plan.
- A clear administrative mandate for this process including: the provision of necessary materials, meeting space, and adequate staff coverage to allow meetings; and support and mandate for all departments in the program to help implement action plans.

We know that finding time to meet and providing sufficient staffing for residents during these meetings are major challenges. We will offer some suggestions on how to meet these challenges. Once you have conducted several such meetings, it may be helpful to review with administrators how this process can be more effectively implemented long term in your program.

Using the *Outline*

It is recommended that direct care staff first be taught the process for solving a problem or challenge with an individual with dementia. The Outline explains the

sequence, the rationale for each step in the problem-solving process, and the items to consider when going through each step. Case studies are provided so that staff can practice these new skills. Guidelines for implementing actual problem-solving sessions for individuals with dementia are provided.

Length and Frequency of Sessions. Ideally, the initial training should be a 3 hour session.

The structure of the training might be as follows:

- The process and rationale of effective problem-solving (60 minutes).
- Break (15 minutes).
- Case study (45 minutes)
- Break (15 minutes).
- Practice with an actual resident from your facility (45 minutes).

This initial 3 hour training helps staff understand the process, allows them to practice the process before it is actually implemented, and to come up with an action plan for a real resident that will assist them with their duties.

If it is not possible to conduct a 3 hour session in your facility, here are four options for modifying the process:

- Review the problem-solving process and a case study in one session (2 hours). Apply the process to your own resident in a separate session (1 hour).
- Hold three separate, 1-hour sessions: the steps in the problem-solving process (1 hour), review a case study (1 hour), apply the process to a resident at your facility (1 hour).
- Review the problem-solving process, skip the case study and apply the problem-solving process directly to a resident in your facility case in one session (2 hours).

- Walk through the problem-solving process by directly applying the process to a resident at your own facility and develop an action plan, while incorporating key concepts and the rationale about the process while you are working through your own case (1 hour).

There are suggestions later in the chapter of how to incorporate the problem-solving process into the routine of your facility once staff understand the process involved.

The Components of the Problem-Solving Process

The following topics should be covered to teach staff an effective problem-solving strategy by teaching them how to:

- Determine when an action plan is needed;
- Challenge assumptions and labels about the person and behaviors;
- Set the stage: Put the individual first;
- Define the behavior or problem;
- Identify the triggers and responses to the behavior or situation;
- Determine the function of the behavior;
- Gather more information for the assessment;
- Develop a person-centered action plan;
- Implement an effective action plan;
- Evaluate, re-assess and modify the action plan.

There are several ways to use the Outline to teach this material:

- You can work through the Outline step by step using the key points and the exercises to create discussion.
- You can choose a client or resident from your program, whom staff have found challenging and use that person to teach the steps and create an action plan.

- Or, we have included a case study about a resident's difficulties at mealtime which has questions throughout the outline to allow staff to practice the steps of problem-solving and action plans. The entire case study is on the CD to be used as a handout.

Below are the steps with rationale, resources, and things for you to think about before you teach this process.

Determine when an action plan is needed.

Typically, individuals and their behaviors are labeled as “problems” or “challenges” and therefore in need of an action plan. Many times, a problem is identified when direct care and professional staff are having difficulty providing the medical or physical care to the resident. It is imperative, however, that a closer look is taken to determine whether a problem is truly a problem which affects the individual's quality of life and/or care. Sometimes simply changing the way we view the problem and the challenging individual can dramatically change how we provide care to an individual.

The *Outline* offers factors to consider when identifying a challenging or problem situation:

- **Who is it really a challenge for? Staff? Or the individual with dementia?**
- This is a good opportunity to provide examples of when the individual's lifestyle choices or preferences are simply inconvenient for staff or do not fit into the schedule or routine of your facility. For example, the individual does not like to get up early; the person worked nights so he stays up at night and sleeps during the day; the person has obsessive compulsive disorder and requires five glasses of water in his room.

- **Is the problem actually a sign of well-being? Does the problem affect the individual's well-being?**

The indicators or signs of well-being were identified by Tom Kitwood, in his book, *Dementia Reconsidered: The Person Comes First* (1997). In order for staff to understand the importance of these indicators, you may wish to have the staff review the list of indicators and invite them to share which indicators are particularly important to them in their life. These are listed in the *Outline*.

Then it would be helpful to discuss with the staff when the challenge is really an indicator of well-being for the individual. For example, an individual with dementia leaves his room for a little while, then returns to his room and becomes incredibly upset and agitated. He starts complaining loudly to the nurse that someone is trespassing and breaking into his room and taking his belongings. This becomes a regular occurrence. A typical response would be to have a psychiatrist address his "paranoia" and "agitation," which places him at risk for sedation, adverse side effects and other health complications. However, upon closer examination it appears that the individual is becoming upset because housekeeping is taking his laundry and sending it to be cleaned. In that light, there are a few indicators of well-being: he has the ability to communicate his concerns; he initiates social interaction; he has a sense of self-respect and asks others to respect his property; and he can express a range of emotions. By getting the full picture of the behaviors and identifying indicators of well-being, the situation can be more easily solved (e.g., teach him to put his clothes in a hamper or to take his clothes to the laundry room), and

solved in a manner that validates and supports his indicators of well-being.

Next it is important to discuss when the person's behavior affects his or her well-being. For example, a woman with dementia has some significant communication challenges and likes to push other residents in their wheelchairs. However, she sometimes hits staff when they try to stop her. This is a safety risk for staff and other residents as well. Some indicators of well-being that may be affected negatively by this scenario include: her ability to express wishes and her need to be helpful to others. Thus, an action or plan should include ways to keep staff and other residents safe while, at the same time, helping the woman achieve her indicators of well-being. In this instance, staff might help her find other ways of expressing her need to be helpful safely, such as folding towels or pushing residents under carefully controlled conditions.

- **Are there indicators of ill-being that affect quality of life?**

Again, it may be helpful to have staff review the indicators of ill-being and identify which factors have a particularly negative impact on them. Then, provide case examples of problem situations with indicators of ill-being.

- **Does the problem affect the quality of care?**

Provide examples of a problem that affects the quality of care that the individual receives. These might include personal hygiene, physical status, or medical care.

- **Does it affect the person's relationships with family, friends and staff?**

Relationships with others are important for people generally. We possess a fundamental need to be social and

interact with others, even if it is to a minimal degree. To make this point, have staff reflect upon the meaningful relationships they have in their lives, either with friends, people they date, or family. Then, provide some examples of how the behaviors or challenging situation affect or interfere with the individual's relationships with staff, friends and family.

Even if a behavior or situation causes more stress and anxiety to the direct care staff than to the individual with dementia, this still may be a problem that requires an action plan. The well-being of the direct care staff is as important as the well-being of the person with dementia because it can significantly impact their relationship and interactions with residents. It is important to address the behavior or situation if the stress on the caregiver ends up affecting their ability to function or their relationship with the resident. For example, it is a concern when staff will only interact with the individual to provide the required physical care, when staff provide care as quickly as possible and avoid any other interactions with this individual, or when staff are quick to become irritated or impatient with the individual. For many individuals with dementia, interacting with staff may be one of the few opportunities for engagement directly with another human being, especially if they are no longer able to socialize or initiate conversations with others on their own due to their impairments.

Assessing quality of life and caregiver burden or stress. Sometimes it is helpful to use standardized checklists or assessment tools to help identify the individual's quality of life to determine the extent of the "problem," (and later on, to help with determining whether an intervention is working or not), or to determine whether

interactions with the individual are causing staff burnout or frustration. For example, you may wish to refer to *Quality of Life in Alzheimer's Disease: Patient and Caregiver Report (QOL-AD)* (Logsdon, Gibbons, McCurry, & Teri, 2002).

You should also assess the stress experienced by direct care staff when caring for the individual with dementia. There are a number of caregiver burden assessment scales developed for family caregivers which can be adapted for assessing caregiver burden for direct care staff. Or, you can explore the presence or absence of signs of well-being and/or ill-being in your direct care staff as well.

Challenge assumptions about and labels of the person and behaviors.

Much of the problem-solving process includes changing the way the direct care staff view, treat, and interact with the individual with dementia. It is easy and common to jump to conclusions regarding the person with dementia and their abilities, as well as the causes of their behaviors. However, making quick assumptions and labeling interfere with providing person-centered care; labeling strips away the opportunity for the individual to engage in meaningful activities and participate successfully in their life and relationships with others.

The *Outline* emphasizes the need to help staff reflect and understand how these labels and assumptions can negatively impact the individual with dementia. Below are some materials and exercises that may help with reinforcing the points made in the *Outline*.

No one likes to be stereotyped. Dementia care is not the only area where society has fought the negative consequences of stereotyping and labeling. As human beings, we strive to preserve our identity and individuality and to recognize and value differences. Stereotyping and

labeling are counterproductive to these goals. They are oversimplistic descriptions of a set of generalized characteristics, and do not acknowledge the individual's life experiences and preferences. Stereotyping or labeling also often implies a value judgment. Labels can be extremely harmful to an individual and their relationships with others, particularly when others act on the assumptions that arise from the stereotype or label, or have lowered expectations. There are some exercises in the outline and more on the CD for looking at these issues.

The stigma of dementia. The word dementia invokes a number of responses, including words like crazy, senile, helpless, losing one's marbles. People may imagine individuals who cannot do anything for themselves and no longer lead meaningful lives. These images also result in assumptions that individuals with dementia can no longer experience good quality of life, and should be locked away, feared, and pitied. The stigma and stereotypes about dementia result in lowered expectations of individuals with dementia regarding their abilities, their value in society, and their potential. As a result of lowered expectations, the individual with dementia is provided with fewer opportunities to participate in care and to have their psychosocial needs addressed.

Therefore, it is important to point out to staff what these stereotypes and assumptions are and how they easily sneak into our thinking. Ask staff to be honest with themselves and explore whether these assumptions and stereotypes exist in their minds regarding dementia generally, and how this may affect their interactions and relationships with individuals with dementia. It is very helpful if the trainer admits to struggling with this and gives a personal example. Staff are far more willing to be honest about these sensitive issues, if the trainer takes the lead. After all, we all label people and residents

sometimes. You should also point out to staff that they should not be chided or feel embarrassed for having these stereotypes or assumptions, as it is easy to do. The most important step for staff is to become aware and catch themselves with using these stereotypes and assumptions and to shift the focus to the individual and their abilities instead.

Labeling of behaviors of persons with dementia. Those in the field of dementia care have tended to use labels to describe the individual's behaviors, which removes the focus from the individual. This has led to words like aggressive, combative, disruptive, wanderer, feeder or sundowner

In describing people with dementia, every word ending with 'er' or 'ing' (such as, feeder, toileting) reduces the person to an activity, the behavior or the diagnosis. These words are used regularly; they imply passivity, helplessness, and objectification. In addition, these labels usually lead to negative judgment on the individual (e.g., uncooperative, lazy, demanding, manipulative).

Because of the simplicity and lack of details with a label, there is too much room for interpretation and variation. Single words have very different meanings for different staff. The exercise below helps staff think about the difference between single, labeling words and more descriptive language.

Exercise: Have everyone write down what behaviors, challenges and emotions they think of when they hear the words "wanderer," or "sundowner." Compare their descriptions and note how different they can be. Then have the staff try and find alternative ways to describe common labels.

<u>Label</u>	<u>Alternative</u>
Wandering	Likes to walk
Incontinent	Toileting difficulty
Attention-seeking	Likes to socialize and interact with others

Why change our language in dementia care? Language is rooted in personal beliefs, experiences, professional practice, and the culture to which we belong. Language that promotes stereotypes and stigma related to individuals with dementia is incompatible with the philosophy of person-centered care.

A pioneer in the field of language and labeling in dementia care, David Sheard (2003) has said, “The challenge in moving toward person-centered care is in accepting the power of language and its role in the negative culture (the old culture) of dementia care. Helping staff and ourselves to look at and change our use of language, is to begin to empower people with dementia. If we recognize behavior as a means of communicating, then we acknowledge that these are people with feelings, needs, and desires. When we label them, we dismiss them without considering their humanity.” Person-centered care demands person-centered language.

The current language that most of us use fuels poor practice. Beginning to think carefully about the words we use to describe people and to describe behavior is one piece of the jigsaw of working towards a culture of person-centered dementia care.

Identify the stereotypes and labels that may affect how care is provided. It is important in the problem-solving process to help staff identify their own assumptions and generalizations regarding the problem behavior and the person with dementia in need of an action plan. Explore with them how these assumptions and attitudes may affect how they interact with the person and provide care. For example, it may result in decreased patience with the person, or

doing too much for the person instead of allowing the individual to participate and make choices in their care.

It is important to emphasize to staff that they are not being judged for having these assumptions and attitudes towards individuals with dementia. This is a natural human tendency.

Set the stage: Putting the person first.

Person-centered care asks us to

- Emphasize the importance of feelings;
- See all behavior and communication as meaningful;
- Recognize well-being and ill-being;
- Focus on strengths, abilities, and core qualities of the person; and
- Compensate for the cognitive limitations caused by dementia.

In helping staff understand the importance of putting the individual first, it is important to help them reflect on their own life history, preferences, lifestyle and values, and to discuss and point out differences and similarities with their peers. In the outline and on the CD are some exercises and questions that you can use to help emphasize the importance of identifying this information for developing a person-centered action plan.

Define the behavior or problem.

It is important that the behavior or situation is described in detail and in objective terms. Staff should be provided the opportunity to identify and practice defining the behavior.

Objective and concrete descriptions of behavior: As mentioned previously, using labels to describe the behavior results in confusion and differences in what behaviors the label is referencing. Describing the behavior in more detail results in consistency and agreement of

what behavior the action plan is actually targeting. The exercise below is similar to the previous one, but gives staff practice in developing more detailed and less stereotyped descriptions of behaviors.

Exercise: Have staff identify more descriptive and concrete terms in describing a behavior or challenging situation rather than a commonly used label. First provide an example or two of better descriptions for a label. For example:

<u>Label</u>	<u>Examples of better descriptors</u>
Physical aggression during care	- hits staff during showers - bites staff while staff assists with brushing teeth - kicks and pinches staff while staff assists with undressing

Help staff understand that by reframing behaviors in this way, we often end up seeing the person differently. If we understand that the person is kicking because he is afraid of a stranger coming into his space and undressing him, we are more likely to empathize with him than if we just label him as physically aggressive.

Identifying frequency, scope, duration: Describing the behavior more accurately allows us to measure the effects of our action plans more easily. Provide examples of defining the behavior in terms of the frequency, scope and duration.

Identifying warning signs that there may be a potential problem or unmet need: It is easy and useful to teach staff to identify the **warning signs** that a person with dementia is becoming distressed, or about to engage in the behavior; an exercise is included in the *Outline*. (See Session 6 for more discussion of warning signs.)

Identify the triggers and responses to the behavior or situation.

First, staff should identify exactly what is going on when the behaviors occur, to determine what triggers or sets off the behaviors. In other words, they should identify: who, what, where, and when the behaviors occur. (See Session 6 for more discussion of this.)

In addition, staff should identify under what circumstances the behavior does not occur and when positive behaviors are promoted (e.g. successful staff approach/strategies).

It is also important to identify the **response** to the individual's behavior by others, as they provide big clues as to why the behavior is happening. People do things to achieve a certain result or outcome. For example, if a staff member gives a woman ice cream to keep her from yelling, then the yelling may serve the purpose of getting ice cream and/or social interaction.

In addition, by observing how the individual reacts when the direct care staff try to intervene or respond to the behavior, it can help identify successful and unsuccessful strategies to include as well as identify the possible causes or function of the behavior. For example, if staff respond to an individual yelling by placing them in a quiet room assuming the person is over-stimulated, but the individual continues to yell, then it is a sign that over-stimulation is not the reason why he or she is yelling. Or, if staff respond to the individual resisting care by singing, and the individual then becomes more cooperative, this may indicate that the individual is anxious or scared during care and singing calms her. Singing would be something to include in the action plan to help keep the individual calm.

Determine the function of the behavior.

Review the causes of behavior outlined in Session 6 and that behaviors typically:

- Communicate an opinion or preference;
- Communicate an emotion;
- Cause someone or something to stop;
- Help to meet an unmet need.

Gather more information for the assessment.

There are a variety of assessment methods and tools to help you answer the questions necessary to develop an action plan.

Formal assessment tools. There are a number of formal assessment tools that can help staff collect the necessary information to obtain more information about the person, define the behavior and assess the causes of behavior. Formal assessment tools are those that have been developed by researchers and clinicians and tested to ensure that they are actually collecting the information that they should and that it is successful in collecting information that is consistent and reliable.

Some formal assessment tools require some familiarity or training to use the tool properly. However some helpful formal assessment tools which do not require extensive training to use include:

- *Cohen Mansfield Agitation Inventory* (Cohen-Mansfield et al., 1989). This is a good tool to help better define agitated behaviors.
- *Geriatric Depression Scale.* (Yesavage et al., 1983) This is a tool used for identifying signs of depression in older adults.
- *Identifying Pleasant Activities for Alzheimer's Disease Patients: The Pleasant Events Schedule - AD.* (Teri and Lodgson, 1991) It is important to

know what the individual still enjoys to help encourage positive behaviors and design meaningful activities.

- *Pain AD.* (Lane, et al., 2003) This is a particularly good form to assess whether the individual is experiencing pain. Pain is one of the causes of behavior that is most frequently missed.

Identify whether another staff member can assist the direct care staff in collecting this information, such as a nurse or a social worker.

Informal assessment tools. The use of informal assessment tools is the most common way of gathering information for this problem-solving process. This includes the use of communication log books, reviewing the chart, behavior logs and observation. Introducing staff to the idea of observing and recording behavior can be a useful way to help them become better problem-solvers (and better observers, too).

There are many examples of behavior logs discussed in the dementia care literature. Keeping a log for several days is one way of gathering data about the person's behavior. A log can be useful in determining if there is a pattern or a set of circumstances that seem to trigger the behavior. We have included a sample *Behavior Monitoring Form* (for collecting frequency data, especially if it is a behavior that happens several times a day) and *Behavior Observation Form* (for documenting possible triggers or causes and responses to the behaviors). You can use both forms at the same time or by themselves.

You can also develop your own forms to find out more specific information. For example, see the sample *Documentation Form for Mrs. Smith.*

A discussion should occur about how behavior logs can best be used in your program, including:

- Challenges to gathering information in your setting;
- What methods are likely to be most effective, considering time and documentation requirements;
- Feedback on what forms are most “user friendly” for staff;
- Suggestions of ways to modify the forms.

Importance of good observations skills.

It is also important to get direct care staff into the habit of paying attention to their experiences, what strategies haven’t worked and what strategies they have tried that have been successful or helpful. This will help them identify possible causes of the behavior, and also possible suggestions for interventions. An exercise is included in the Outline.

Develop a person-centered action plan.

Having a written action plan in place ensures that all staff are consistently using the same interventions. Each action plan should include:

- A brief introduction to the person and the action plan, which will include life history and background of the person, personality traits and coping abilities and traits.
- Description of the problem or behavior and the possible causes of it;
- Identification of the goals for the action plan;
- Description of strategies for setting the tone with this person and,
- Description of the strategies and interventions.

Included on the CD is an Action Plan for Assisting Mrs. Smith with a Bath, a sample plan of action outlining the steps and interventions for staff.

Identifying the goals of the action plan:

Your job is to teach staff how to write concrete, measurable, realistic goals.

- **Provide an example of a clear, concrete goal.** For example, “Mrs. Smith will not punch or kick during her shower more than 1 time a month.” Or, “Mr. Brown will attend 1 activity per week.”
- **Provide an example of what a realistic goal looks like.** For example, if the individual tries to bite staff approximately 4 times a week while they assist with brushing her teeth, the goal might be, “Mrs. Smith will not bite staff while assisting with brushing her teeth more than 1 time a week.” A non-realistic goal is when the goal is significantly different from the actual frequency of the behavior. For example, for a behavior that occurs 5 times a day, an unrealistic goal to start would be to reduce it to less than 1 time a month.
- Most importantly, an action plan should include a goal that **reduces the occurrence of the challenging situation, and also introduces a positive behavior/situation** that is the opposite or in its place of the negative or challenging behavior. This positive situation or behavior should be based on the individual’s abilities and strengths. For example, for the goal “Mrs. Smith will not punch or kick during her shower more than one time a month” the accompanying goal could be, “Mrs. Smith will wash a part of her body with a washcloth 6 times a month during her shower.”

Note to Trainer: There are additional samples and exercises on the CD of goal setting.

Strategies for setting the tone: This section reminds staff of the strategies that they have identified that make a difference in setting the tone for this particular resident.

This includes suggestions on how to reduce the individual's anxiety and confusion, including modifying the environment and what activities to have the person engage in before the challenging task to help him or her relax.

Identifying strategies for the action plan:

- Once you do a thorough assessment, the solutions and strategies to address the problem may be quite clear. However, this is where you emphasize the need for creativity and flexibility by your facility to try strategies. The strategies should provide suggestions on how to approach and interact with the individual based on what was identified as working and not working. There may be other strategies that staff will want to try based on new information learned from the assessment, such as accommodating for the person's life history, habits and preferences. For example, if it is known that the individual prefers to sleep in the mornings, then perhaps one strategy is to allow him or her to sleep in before giving assistance in getting out of bed.
- In addition, there should be strategies for engaging the person in meaningful activities. Many times, a challenging behavior arises because he or she has nothing meaningful to do. If the person is truly engaged and enjoying the task, it is less likely that staff will encounter resistance.
- Giving the individual a feeling of control and choice is extremely important. Whenever possible, the strategies should include opportunities for the individual to make choices, even if they are very simple choices (e.g., milk or juice).
- Regardless of the strategies, there should always be encouragement, praise, rewards and acknowledgement for every step of the task or successful interactions with the individual.

This should be based on what the individual enjoys as determined in the assessment. For example, "Mrs. Smith should be thanked every step of the way while she is cooperating. Also hold her hand at the end of the task when it was a successful interaction and talk to her for a few minutes. She really enjoys touch and talking about her daughters." Having staff do this helps them recognize how often and when the individual with dementia is cooperative and pleasant.

Suggestions for how to handle resistance: First, give staff tips on how to avoid injury. (See *Outline*.) These can be very difficult behaviors. We believe that it is very important to provide staff with guidelines of what to do during a difficult interaction, including how to keep themselves and others safe, and how to respond to the individual. This also helps to reinforce the notion that it is okay if you are not successful with every interaction.

Suggestions on how to respond to a behavior should take into consideration what the individual is trying to accomplish with their behavior. If there is a different way that the individual can get his or her needs met that is more adaptive and positive, then staff should try and set up circumstances where that is encouraged. However, if the individual achieves his goal in a maladaptive way, then the individual should not be rewarded for that behavior. For example, if Mrs. Cross yells because she enjoys the attention and concern from others, then the staff should not respond directly to her when she is yelling, assuming there does not appear to be an emergency or a more immediate need. Instead, staff should give her attention and talk to her when she is not yelling.

The *Outline* points out common ways for staff to respond, both positive – re-approach, re-direct, and validate, and

negative – punishment, reality orientation, and “therapeutic fibbing.” It is important to define and discuss these with staff. There is a staff exercise about lying on the CD if you want to explore the topics of therapeutic fibbing and lying more fully with staff.

Implement an effective action plan.

The *Outline* points out some important tips to ensure success with the action plan:

- **Plain, easy-to-follow directions.** Instructions should be in short sentences, simple and step by step.
- **Widespread dissemination of action plan.** It will be important to identify how best to let everyone know there is an action plan, and where the action plan will be kept so that all staff have easy access it (e.g., in-services, behaviors book for staff). It might be helpful to have a discussion with the direct care staff in the training to brainstorm and get their initial thoughts on how best to let people know about the plan and the strategies in your facility.
- **Consistent use by ALL staff needed.** All staff at the facility, regardless of their role (care or administrative), should acknowledge and praise each other when they are trying to use the plan, and also all staff should model for others how to implement and follow the plan.

Evaluate, re-assess and modify the action plan.

Remind staff that there needs to be monitoring and data collection to determine whether the plan is working. Staff should also be reminded that this is a continuous process and the strategies first identified may not always work.

It is important to gather feedback from staff once the plan is implemented for a period of time and to review the data to see if the plan is really working or whether there are parts of the plan that are too difficult to

implement. You can also use other data identified earlier to determine whether an action plan is effective. In the initial problem statement, staff have developed baseline information about the frequency and elements of the problem; this can be compared with what is happening once the action plan is in place. You can use assessment tools mentioned previously, such as assessing whether there is an improvement in the person with dementia’s quality of life and/or a reduction in caregiver stress.

Staff may have to do a re-assessment or re-evaluation on the possible causes of the behavior, especially if there have been changes in the resident’s environment or status. Based on this information, the action plan should be revised accordingly.

Facilitating an Actual Problem-Solving Session

Now that the staff have a better understanding of the process involved for effective problem-solving and an opportunity to practice this process, it is time to help staff with the challenges they face and improve the quality care and life for the residents in your setting. Below are tips and suggestions for leading actual problem-solving sessions.

Participants should include staff from nursing, including direct care staff, housekeeping, maintenance, activities, social services, dietary, and rehab, depending on the nature of the problem under discussion. You may also wish to include family members, who can provide support and materials for any interventions that are created.

Meeting times can also be rotated to accommodate staff from different shifts; as with all training in residential care, this is a challenge. **It is our belief that these meetings should be mandatory for all shifts and that staff should be paid to attend.**

It is important to have a skilled facilitator and a notetaker. In our experience, the ideal schedule for problem-solving meetings is twice a month for one hour. Perhaps in your facility some other schedule will be easier to implement, such as bringing staff together for shorter sessions more often (e.g., 30-40 minutes weekly) to cover a portion of the agenda. If separate meetings are not possible, you may wish to use a few minutes at shift change, to complete some of the steps until an action plan is developed. Or, you might use this process during resident care planning meetings, but **it is imperative that at least one direct care staff member be included as part of the process**, since they know the residents and the problems best.

Preparing for the meeting: Before the meeting, you may wish to have staff identify some possible residents and/or behavioral issues in need of an action plan. Then develop an agenda for the meeting. Remember, the goal of each meeting is to have a written end so that the staff can see that they accomplished something (e.g., written description of the behavior).

You may want to have the following materials on hand: nametags, markers, newsprint and easel, agenda, and snacks.

Facilitating the meeting: You will be using one meeting to focus on an individual that staff believe needs an action plan. Focusing on a specific resident enables staff to define the problem, to talk through specific situations when the behavior seems to occur and to identify strategies for intervening that have worked and haven't worked. This process teaches staff how to systematically work through a problem. Once staff have answers to some of the questions, they are then ready to put together a plan of action for responding to the problem.

The meeting should include introductions if they don't all know each other and brief ground rules for respectful interaction. You may want to begin with some of the successes staff have had recently in their jobs. This is an effective way of acknowledging the creativity, energy and efforts staff are giving to your program.

Work through the steps of the problem-solving process together and then assign someone to write up the action plan, including all the information staff have identified as well as the strategies. Decide together on the format and how best to present the information in the action plan. You can refer them to the sample action plans provided in this chapter as well. Ask staff to help identify places where the action plan should be kept where it will be easily accessible to all staff.

Following up after a problem-solving session.

If the plan of action is not completed by the end of the meeting, invite two or three staff to form a workgroup to finish it. You might offer to help them with the final details. You will also need to identify a series of questions for the accompanying sessions. Remember, the goal is to focus on a resident concern and to develop an intervention plan. Each problem-solving session should have a concrete product for staff to refer to.

The facilitator should also assist with any items for follow up that are necessary to successfully develop and/or implement the plan (e.g., typing up the plan, ensuring documentation of behaviors). **Communication by the facilitator with other administrative staff is key to successful implementation.**

Materials on the CD for this session:

Staff Handout: Steps in the Problem-Solving Process (major points from the *Trainer's Outline*)

Facilitator's Guide: Problem-Solving Agenda (assists with running a problem-solving session)

Staff Handout: Problem-Solving Outline (one page)

Sample Action Plan for Assisting Mrs. Smith with a Bath

Sample Documentation Sheet for Mrs. Smith

Sample Resident Biosketch

Sample Behavior Monitoring Form

Sample Behavior Observation Form

Case Study Instructions

Case Study 7A: Difficulties at Mealtime

Trainer's Worksheet for Case Study 7A

Case Study 7B: A Woman Who Collects Things

Additional Exercises to Use with Staff

SESSION 7

OUTLINE FOR

TRAINER

Teaching Staff Effective Problem-Solving Strategies

Introductory comments

Staff who work directly with people with dementia have important and challenging jobs. Often you know the residents or clients better than anyone else. You are a very valuable part of the care and treatment team.

You previously learned about some of the causes of challenging behaviors for individuals with dementia. This session will give you the skills to be able to participate in a problem-solving process and the development of an action plan for individuals with dementia. As a team we will work together to find a way to include all staff in this process to improve quality of life for individuals with dementia.

What are the goals in caring for a person with dementia?

To provide quality care in a supportive environment and to improve quality of life.

We provide quality of life and quality care by

- Attending to the person's physical condition;
- Promoting personal hygiene;
- Providing appropriate medical treatment;
- Ensuring the individual's comfort;
- Maximizing physical well-being, mood, psychological well-being, and interpersonal relationships;
- Enhancing ability to successfully participate in meaningful activities;

- Assisting as needed with financial situation;
- Overall assessment of self and self-esteem.

Why is learning an effective problem-solving process important?

Problem-solving can

- Improve quality of care;
- Improve quality of life;
- Improve relationships between you, the residents or clients, and their families;
- Reduce your stress.

This is important because:

- Caring for individuals with dementia can be very challenging, frustrating and stressful at times, but also very rewarding and meaningful.
- You play an important role in the lives of individuals with dementia and need to have input into the development of strategies to address challenging situations you encounter.
- You have valuable insights and information regarding the needs and preferences of the people you work with and approaches that have and have not worked.
- This problem-solving process gives you the opportunity to share what you know with your colleagues, to be creative in trying new approaches, and to develop more meaningful relationships with the people you care for.

The problem-solving process requires not only the exploration of the behaviors themselves, but painting a **complete picture of the behavior** in the context of the person's

- Life history, personality and preferences;

- Current environment;
- Strengths and abilities; and,
- Medical, physical and psychosocial needs.

Together we are going to learn how to problem-solve and develop action plans.

Trainer: Give staff the handout with the steps.

The steps in the problem-solving process are as follows:

- Determine when an action plan is needed;
- Challenge the assumptions and labels about the individual and the behaviors;
- Set the stage: Putting the individual first;
- Define the behavior or problem;
- Identify the triggers and responses to the behavior or situation;
- Determine the function of the behavior;
- Gather more information for the assessment of the problem;
- Develop a person-centered action plan;
- Implement an effective action plan; and
- Re-assess, evaluate and modify the action plan.

Determine when an action plan is needed

When does a person or situation need an action plan?

Usually, an individual, a behavior or situation is identified as needing an action plan when there is a problem.

Definition of a problem. A problem is often defined as a situation or circumstance that interferes with achieving a goal or accomplishing a task.

In other words, a problem when caring for an individual with dementia is any factor or situation that interferes with your ability to provide quality care. Or that significantly

affects an individual's medical, physical, psychological and social well-being.

Important questions to ask:

- **Whose problem is it?** It is important to clarify initially whether it is your problem, the resident's problem, or the program / facility's problem. Is it being labeled as a problem needing to change when it arises from the person's lifestyle choices or preferences that are inconvenient or don't fit with our way of caring for the residents?

Examples: Mrs. Montgomery doesn't want to get up in the morning for 7:00 am breakfast. Whose problem is that? If Mr. Peters doesn't like to bathe at night, whose problem is that? (**Trainer:** Come up with your own examples from your program.) An action plan should be developed if the problem is significantly affecting the individual's quality of care, quality of life, or relationships with others.

- **Is the problem initially identified actually a sign of a person's well-being? Does the problem interfere with the person's well-being?**

Signs of well-being identified by Tom Kitwood include:

- Ability to express wishes and concerns
- Ability to achieve bodily relaxation
- Opportunities to express sensitivity to emotional needs of others
- Opportunities for creative self expression
- Use of humor
- Taking pleasure in aspects of daily life
- Being helpful to others
- Initiating social contact
- Showing affection

- Having self-respect
- Expressing a full range of emotions
- Accepting others
- **Are there signs of ill-being due to the problem identified?** If you observe the following signs of ill-being, the person with dementia needs attention, problem-solving, and an action plan:
 - Unattended sadness or grief
 - Sustained anger
 - Anxiety
 - Boredom
 - Apathy and withdrawal or isolation
 - Despair
 - Physical discomfort and pain
 - Lack of social interaction and participation in activities
- Individuals or their behaviors are typically identified as a problem when the behaviors make your jobs more difficult. However, it is just as important to identify and develop action plans for those who are withdrawn and depressed.
- **Does the situation or behavior affect your ability to provide good care to the individual?** An action plan may be required when the person with dementia becomes physically uncomfortable, is not clean, or does not have the maximum benefit from medical care due to the challenges in providing care.
- **Does it affect the person's relationships with family, friends and caregiver?** When you or others don't want to help, interact or socialize with the individual with dementia, or experience a significant amount of caregiver burden or stress related to this person, then it is a problem. Positive interactions with others are important to most people and affect quality of life, not just for the individual with dementia but also for caregivers, meaning YOU!

- **The more areas of care and quality of life that are affected by the challenging situation, the more important it is to develop an action plan to address the challenge.**

Challenge assumptions about and labels of the person and the behaviors

Discussion question: Have any of you ever experienced stereotyping or labeling? For example, maybe you were labeled as a jock or a geek or a loser in high school. Racial or ethnic stereotyping is common as well.

- What labels have you experienced?
- What does it feel like to be labeled or stereotyped?
- What is the result for the person who is labeled?
 - Seen as less than whole;
 - False assumptions made about person;
 - May be seen as less competent than really are;
 - Treated unkindly or avoided;
 - Segregation;
 - Racial profiling.

Key points:

- **No one likes to be stereotyped or labeled.** We like to be seen and appreciated as individuals with our own identities and unique differences.
- **Stereotypes of and assumptions about people with dementia lead to lowered expectations of their abilities and less empathy for them as people.**

Discussion question: What stereotypes and labels do we have or hear about people with dementia?

Examples: Crazy, senile, typical of aging, confused about everything, unaware of anything around them, helpless, unable to care for themselves at all, unproductive, unable to learn

or remember anything, mean or angry, childlike, unable to understand anything said to him or her, particularly if the individual is unable to speak

- **Labeling of behaviors shifts the focus away from the person.** Instead, labeling reduces the person to an activity, the behavior or their diagnosis.
- **Stereotypes and labels prevent person-centered care.** Person-centered care requires putting the person first and understanding the behaviors in context of the person, life experiences and preferences. All of these factors influence how the person responds to the current life situation and experiences of needing care.
- **When trying to solve a problem, it is important to identify the stereotypes and assumptions regarding the individual and the problem.** Discuss how an individual or problem is being described and whether there are labels and assumptions being applied.
- **Identify what information is or is not known about the person or problem, including:**
 - Who the individual is and their life history;
 - The individual's abilities, strengths and weaknesses; and
 - The behavior(s) or challenging situation.
- **Consider and challenge yourself on how these stereotypes and labels may affect how you provide care and interact with the individual with dementia.** Breaking down these stereotypes and labels may result in a more successful interaction with the individual with dementia because it allows for more empathy and understanding towards the individual.

Exercise: Have everyone write down what behaviors, challenges and emotions they think of when they hear the words

wanderer, or sundowner. Compare their descriptions and note how different they can be. Then have the staff try and find alternative ways to describe the behaviors that get labeled.

<u>Label</u>	<u>Alternative</u>
Wandering	Likes to walk
Incontinent	Toileting difficulty
Attention-seeking	Likes to socialize and interact with others

Set the stage: Putting the individual first

Exercise: Ask staff to share a significant life event that changed who they are and how they think. As you debrief, help staff understand why it would be important to know this information about residents.

Exercise: Have staff identify what activities or things they really value and enjoy, such as types of music, types of food. This exercise can clearly illustrate how everyone likes and enjoys different things.

Exercise: Ask staff how they feel about privacy, their bodies and nudity. Point out how some people feel more strongly about privacy than others. This is to help point out the differences in people regarding values and attitudes.

Trainer: There are additional exercises on the CD.

Key points:

- A person-centered action plan requires putting the person first, acknowledging their uniqueness, their strengths and abilities. Behaviors of an individual with dementia are always influenced by the person's life history, preferences, personality characteristics, and their current strengths and abilities. Thus, it is important to gather this information about the person so it can be included in the action plan.

- **Putting the person first challenges and breaks down assumptions and labels.** This can result in a change of attitude and how you interact with the person, which in turn can significantly affect their behavior.
- **Determine any significant or challenging life events in the individual's life, the type and scope of relationships with others, and significant family members and friends.** This includes information about the individual's early life, mental health and substance abuse history, close relationships, names of parents, siblings, spouses, children and grandchildren.
- **Determine the person's past occupation(s) and education.** Sometimes this information sheds light on behavior. For example, an individual who was a nurse on the night shift may walk up and down the halls in the middle of the night now because she is recreating old patterns.
- **To the extent you are able, find out about the person's values, what has been important to them in their life.** This may include religion, spiritual beliefs, or philosophy of life.
- **Learn about his or her personality (including unique characteristics or quirks) and coping skills.** Coping skills during difficult times for individuals can include procrastination, humor, eating, pampering themselves, taking frustrations out on others, yelling at others, drinking, getting into fights, isolation, listening to music, exercising, or problem-solving, among others.
- **Identify medical, physical and psychosocial needs that are particularly important to that individual.** Aside from the medical and physical needs, all of us have needs which include love, comfort, attachment, occupation, identity and

inclusion. Depending on the person, some needs are more important to the individual than others.

- **Explore the history of the person's lifestyle.** Did he or she like to go out, travel? Live frugally or extravagantly? Value privacy or prefer a more communal life?
- **Identify preferences regarding the person's daily routine,** such as awakening and bed times, meal and bathing preferences.
- **Identify what the person still enjoys.** This includes activities, social interactions and praise, touch, music, and types of food.
- **Identify current areas of strength and/or ability.** These may include:
 - Skills that are now habit or were used frequently in the past (e.g., a homemaker folding towels);
 - Sense of humor;
 - Ability or desire to help others;
 - Emotional awareness and emotional memory;
 - Social skills;
 - Communication and comprehension skills;
 - Sensory appreciation/awareness;
 - Physical abilities/mobility;
 - Responsive to music;
 - Interest in activities;
 - Long-term memory.

Define the challenging situation or behavior

Describing the challenging situation and behavior in more detail is important to clarify what problem it is you are trying to address. It is also important in order to track and monitor your action plan and see if it is actually working.

Exercise: Have staff practice using descriptive and concrete terms to describe a behavior or challenging situation rather than a commonly used label. First provide an example or two of better descriptions for a label. For example:

<u>Label</u>	<u>Examples of better descriptors</u>
Physical aggression during care	<ul style="list-style-type: none"> - hits staff during showers - bites staff while staff assists with brushing teeth - kicks and pinches staff while staff assists with undressing
Demanding	<ul style="list-style-type: none"> - makes multiple requests throughout the day for assistance - makes repeated requests in a row due to short term memory loss - makes requests for assistance when the individual has the ability to complete the task independently

Key points:

- **Only choose one or two problem situations at a time.** These situations should have the most significant impact on the individual's care and quality of life.
- **Use concrete, objective (neutral) terms to describe the behavior(s) that is observed.** What does the behavior look like? What is the person doing exactly? Who is behavior targeted towards? Remember the cautions against labeling and only describe the behavior or situation with neutral words.
- **Identify the frequency of the behavior.** How often does the behavior happen?

- **Identify the duration of the behavior.** How long does the behavior last?
- **Describe the level or intensity of the behavior.** Does it get worse over time (e.g., louder, faster, more violent)? Does it get less over time?
- **Identify warning signs to prevent the behavior.** If you can identify warning signs, you can often calm the person down or meet their needs before the behavior or situation becomes significantly challenging.

Non-verbal warning signs include *body language* and *changes in physical activity*. Body language may include threatening gestures, clenched fists, reddened face, gritting the teeth, rapid eye movement or refusal to establish eye contact, breathing becomes rapid, forming of frown, person may turn pale or flushed, hands or body may tremble.

Verbal warning signs include raising their voices, speaking faster, muttering, swearing, using obscene or threatening language.

Changes in the usual pattern of physical activity include pacing, wringing hands, throwing things, picking at clothing or becoming withdrawn and quiet, crying, restlessness, repetitive hand movements.

- **If needed, use tools to collect more information about the behavior.** You may have to collect more data before you can adequately define the behavior. While this may seem to be more effort at first, it ensures the development of a successful action plan.

Exercise: Watch a piece of the videotape on the DVD, *Getting Hit, Grabbed, and Threatened*. Ask staff to write down warning signs and problem-solving strategies they see in the video. Debrief together.

Identify the triggers and responses to the behavior or situation

Key points:

- Describe **what** is happening right before, and when the behavior is occurring. What was the person doing right before and at the time the challenging situation occurred?
- Identify **who** is interacting with or around the person when the behavior occurs.
- Determine **where** the behavior occurs. Describe the environment the person is in when the behavior occurs.
- Look at **when** the behavior is occurring. This includes the time of day and any significant events (e.g., shift change)
- Explore the person's **mood** and **feelings** at the time of the behavior. This includes emotions of sadness, happiness, fear, anger, loneliness, anxiety, or others.
- Describe strategies or circumstances when the behavior does **not** occur and the person is responding positively. When identifying situations that seem to prevent the behavior and encourage a wanted or positive response, explore the environment, caregiver approach and communication, accommodating preferences or acknowledging the individual's life history, and physical and/or medical factors.
- Describe the strategies that have been tried that were not successful. This information will give you a better idea of what not to do, and may also provide information as to why the behavior occurs.
- Identify how staff and other people respond to the individual or behavior. This can provide clues as to why the behavior happens regularly. We behave and act in order to achieve a desired result. Do staff stop the task? Come

back later? Keep doing the task? Do staff tell the person to stop the behavior? Get more staff to help? Do other people stop interacting with the individual? Do they try to calm the person down? Do they try and distract or redirect the person?

- **Reactions of the individual to your and others' responses.** This is where to note whether reactions or responses seem to make the situation more or less challenging. Does the person become more agitated and restless as a result? Does the person withdraw or stop interacting? Does it take awhile for the individual to calm down or change their mood?

Determine the function of the individual's behavior

Key points:

- **What is the person trying to communicate through their behaviors?** All behaviors serve a purpose or function and have meaning and communicate the needs and preferences of the individual.
- **Based on the triggers and responses to the behavior, identify the possible reasons why the behavior is occurring.** Remember the categories of possible causes of the behavior:
Environment;
Causes related to the activity itself and preferences that may affect the activity;
Caregiver approach and communication;
Life history and coping strategies;
Physical, medical and psychosocial factors.
- **Identify whether there are any unmet needs of the individual that may be the cause of the behavior.** Remember that in addition to medical and physical needs, psychosocial needs include love, comfort, attachment, occupation, identity and inclusion. A significant

number of challenging behaviors occur because there is some unmet need, and the individual does not have the ability to tell others what their unmet need is and how to meet it. Our job is to make sure that these needs are met.

Exercise: Explore with staff what the symbol of “mother” represents to them (e.g., safety, security, warmth, love, affection). Then point out how a behavior such as calling for one’s mother may represent an unmet need rather than the individual’s actual wish to see his or her mother.

Gather more information for your assessment

Trainer: Pass out the tool or tools you’ve decided to use. (See Suggestions section for discussion of available tools.) Lead a discussion with staff:

- **Sometimes we need to gather more information** to complete and answer the necessary questions to solve the problem before developing a thorough action plan.
- **Where will we use these tools?**
- **When will we use them?**
- **Who will use them?**
- **Good observation skills are the most valuable source of information.** As you are working, pay attention to the possible causes of the behavior, and what strategies have and have not worked for you when providing care with this individual.

Exercise: Watch a videotape clip of a staff person interacting with an individual with dementia. Discuss the approaches and techniques that seem to help the person be successful. Discuss the approaches and techniques that seem to contribute to or cause the challenging behavior to occur. The videotape on the DVD, *Getting Hit, Grabbed, and Threatened*, is a good one for this purpose.

Write clear, measurable goals

- **Describe goals in objective, concrete terms, which identify the number of behaviors within a certain period of time.** Each goal should state the behavior, how often it should or should not occur over a period of time. The format is typically [person] will not [behavior] more than [number] times a [time period], or [person] will [behavior] at least [number] times a [time period].

Examples:

Mrs. Smith’s punching or kicking behavior during her shower will be reduced to once a month at most. Mr. Carson will not bite staff during teeth brushing more than twice a week. Miss Jones will participate in at least two activities per month.

- **Be sure the goal is realistic.** If Mr. Carson has been biting staff every time they try to brush his teeth, it is probably not realistic to expect this behavior to disappear completely. Any improvement should be considered a success.
- **Have goals that not only reduce or eliminate problem behaviors, but also promote positive, productive and desired behaviors in their place.** These goals should be based on the individual’s strength and abilities, as well as preferred activities.

Example: Miss Jones, above, was labeled as being anti-social. Staff felt she spent far too much time by herself in her room. When staff created an action plan and set goals, they developed the following:

Description of behavior based on past history: Alice Jones has always been a shy person who never participated in group activities. Living with other people is a new experience for her. She may be feeling intimidated or scared of group activities.

Goal: Miss Jones will participate in at least two activities per week.

Exercise: In pairs or small groups, write concrete measurable goals for each of the following:

Anna Walker is urinating in her clothing several times per day.

Harold Jackson rarely eats his supper.

Develop a person-centered action plan

Trainer: At this point, you may want to review the parts of the action plan below and begin putting one together using a challenging person or situation from your setting.

Action plans should include the following parts:

- Introduce the person;
- Describe the problem or behavior, including very concrete, non-judgmental terms and specific measurable goals;
- Explain why the person may be doing what she does;
- Identify goals for action plan;
- Describe the strategies and interventions.

Key points:

- **Many action plans simply involve avoiding what causes or triggers the behaviors.** Instead, the goal should be to create a supportive environment or situation that will encourage a more desirable or adaptive behavior to occur.
- **Action plans provide suggestions on how to properly set the tone and prevent or avoid problem situations as much as possible.** These will be based on what factors were identified either to have a positive effect on the individual or to cause or trigger of the challenging behavior. Strategies also include what warning signs staff should look for.

- **Action plans offer interventions on how to encourage a positive, successful interaction or task completion.** These will be based on the assessment that staff have completed of the person, the problem, and successful strategies. Strengths and abilities will also be identified and included.

- **Action plans should include suggestions for responding to warning signs or unsafe situations, including: How to keep the individual safe from harm.**

Examples:

Maintain visual supervision,

Move all hard or sharp objects out of the way,

Move the individual to an area where he or she is less likely to slip or fall.

How to keep others safe from harm, including staff and residents.

Examples:

Not allowing yourself to be boxed in a corner with an angry resident between you and the door,

Staying 5-10 feet away from the individual depending on their mobility,

Moving all residents away from the area,

Never turning your back on an angry resident,

Keeping your hands free to be able to block any strikes, and

Protecting your head and neck.

Stopping the task and re-approaching the individual at a later time.

Re-directing the individual's attention to a meaningful activity.

Validating feelings of frustration or anger of the individual.

Example: George Garrison gets a very angry expression on his face when he thinks others are staring at him. Strategies to try when staff see that angry expression: Take Mr. Garrison to another room.

- **Action plans include all individuals and staff who interact with the individual.** There are a number of individuals who can play an important part in this action plan to help minimize the target problem and to encourage positive behaviors. Such untapped resources are: housekeeping, family members, maintenance, and other residents.
- **Action plans include suggestions for meaningful activities based on the individual's life history, preferences and current strengths and abilities.** Many times behaviors occur because there is an unmet need to engage in meaningful activities.
- **Action plans include opportunities for the individual with dementia to have choices.** Allowing the individual to have as much control over his or her own situation as possible is important, even if it involves small decisions or choices.
- **As part of the action plan, the individual should be acknowledged, praised, thanked and rewarded for any participation or positive behavior at every point of the task or circumstance based on what is meaningful to him or her.** Other ways to recognize positive behaviors can also be provided, such as a snack, candy, or conversation and attention. These rewards should be based on the individual's preferences.
- **Validation and empathy should be part of the action plan.** The individual's mood and emotions should always be acknowledged by staff.
- **Interventions should be realistic.** The more complicated the interventions, the harder it may be for staff to follow the plan. This does not mean that the plan should not have detail; just that the details should not be too complex.
- **Developing interventions require creativity.** This is largely a creative process, and can be interesting and fun.

Many of the successful interventions are identified through trial and error and creative brain-storming.

- **Developing interventions may require flexibility and accommodation by the program or facility.** The problem behavior may stem from the individual's own preferences which do not match the program or facility's routines and schedule.

Action plans should not include:

Punishment. At no time should staff be encouraged to scold, reprimand or punish the individual for the unwanted behavior.

Reality orientation techniques. Reality orientation consists of correcting inaccurate facts or beliefs (i.e., "You don't live at your house anymore." "Your mother died 22 years ago."). This technique is almost always ineffective for those with moderate to severe cognitive impairments, and can cause them to become embarrassed and upset.

Therapeutic fibbing, unless there is imminent harm to self or others. Therapeutic fibbing is when the individual is told a lie in order to accomplish a task or calm the individual down. There is a great deal of ethical debate about the use of this intervention. Whether therapeutic fibbing should be used also may depend on the individual's preferences and life values.

Implement an effective action plan

Key points:

- **Consistent implementation of the interventions is the key to success.** All staff at the facility should follow the plan, including administrators, professionals, paraprofessional, housekeeping and maintenance staff, as well as family members and friends who visit and interact with the individual. Consistent implementation

requires knowledge of the plan by everyone, as well as everyone following the plan.

- **The action plan should be written in simple, short sentences.** This will ensure that everyone can easily understand the plan.
- **Suggestions and interventions for a successful interaction should be broken down to small steps.**
- **Provide frequent in-services of the plan to other staff.** This is especially important when there is a new plan in place.
- **Place the plan in multiple locations that are easily accessible by everyone.** Typically direct care staff and other support staff do not have access to charts. Have staff identify where good locations are for action plans in your facility. Multiple copies should also be made of the plan.
- **All facility staff should be encouraged and praised for any successful interventions.** You and the rest of the staff should also model and show how to use the plan properly to other staff, new staff, and family member and friends.

Evaluate, re-assess and modify the action plan

Key points:

- **Both of the unwanted and desired behaviors should be documented and tracked to see if the plan is working.**
- **Quality of life indicators and assessments can be used to determine whether an action plan is effective.** It is good to review and identify, for example, what are the signs of well-being and ill-being and any changes since the implementation of the plan.
- **Caregiver stress can be another measure of whether the action plan is effective or not.** This is a good indicator as caregiver stress can lead

to fewer quality interactions and poor relationships with the individual, thereby affecting quality of care and life.

- **Feedback from staff, family and friends regarding the action plan should be considered.** This may include feedback on any challenges regarding following the plan, to what seems to be working and what does not seem to be effective in reaching the goals.
- **Evaluation of the effectiveness of an action plan should occur regularly.** This is particularly important when an action plan is first implemented. However, the plan should be given some time to work, as the effectiveness may depend on making sure everyone is aware of the plan and is implementing the plan consistently.
- **Revise the action plan in order to address the challenges in implementing the plan and interventions that are not effective.** Developing an action plan is a process, and involves patience and a great deal of trial and error.
- **The action plan may also need to be revised based on changes in the individual with dementia, or their situation.** Often times, the symptoms and severity of symptoms change over time, and the individual's strengths and abilities tend to change over time. In addition, any changes to the individual's environment will require revision to the plan.
- **To revise the plan, re-assessment of the situation or behavior may be necessary.** The process is the same as before.



SLIPSHEET

Session 8: Helping Staff Understand and Respond to Families

Beth Spencer and Laurie White

Interactive Training Strategies

- Discussion questions with powerpoint slides. This session has different sections, each with discussion questions, addressing different kinds of family issues.
- Four case studies.
- A role-play exercise.
- Exercises. There are several different types of exercises to help staff look at their own values and skills related to families.

Suggestions for Conducting Session 8

Helping Staff Understand and Respond to Families

The goals of this session are:

- To help staff understand and respond sensitively to some of the adjustment issues faced by families whose relatives have dementia, as their relatives move into a program or facility.
- To help staff think creatively about how to make families feel welcome.
- To enhance communication between staff and family members, particularly families who are challenging for staff.

It has been our experience that **many staff members in home care agencies, nursing homes, and assisted living residences are unaware of the issues and concerns of families.** Staff who are sensitive and caring toward residents may be insensitive or actively hostile toward family members due to this lack of understanding.

Using the *Outline*

In this session, we will provide **training ideas for five topic areas.** You may only have time for one or two of them, but we strongly encourage you to do some training on the topic area related to issues for families as they enter the residential care setting. Educating staff about the kinds of pressures and difficulties faced by family caregivers can go a long way toward making staff more sensitive to family concerns.

The five topic areas are:

- Attitude of the institution toward families
- Our own values about families
- Issues for families as they enter the residential care setting
- Creating a welcoming atmosphere for families
- Working with difficult families

At the beginning of the *Outline* are some introductory discussion questions to help staff begin to relate the idea of their own family experiences to those of resident families. The more able they are to identify with the experiences of families, the more sensitive to families they will be.

Attitude of the Institution toward Families

Often the attitude of the institution toward families is reflected in the attitudes of staff. As a trainer concerned about attitudes toward families, you may want to start by thinking about your program's attitude toward families. Assuming that your goal is to make families feel welcome, you may need to do some education with your administration before you attempt to educate staff. Or you may decide that you are not in a position to effect change in your organization with regard to the attitudes toward families. Either way, it is helpful to begin by being aware yourself of how families are viewed as a whole by the institution. Understanding the existing biases in our organizations is an important first step toward change.

Montgomery (1983) developed a useful set of categories for thinking about how nursing homes' views of families are reflected in their policies. The following are some examples for you to consider as you think about your own organization:

- **Family as Outsider:**
 - Resident** viewed in isolation -- not as part of a family unit.
 - Family** viewed as unimportant in the care plan of resident.
 - Little effort to encourage family participation.
 - Staff** members uninformed about families of residents.
 - Staff not encouraged to communicate with families.
 - Staff receive no training about family issues and concerns.

- **Family as Helper:**

Resident seen as part of a family system in only a very limited way.
Family viewed as useful in helping with care.

Little effort to encourage family participation in events.

Family visiting viewed as useful to resident.

Family needs viewed as irrelevant.

Staff communication with families restricted to resident needs.

Staff receive no training about family issues and concerns.

- **Family as Client/Consumer:**

Resident viewed as part of a family unit.

Family viewed as part of the client system.

Family needs and concerns recognized.

Events and opportunities planned that encourage family involvement.

Staff members knowledgeable about residents' families.

Staff encouraged to communicate with families.

Key staff accessible to family.

Staff receive training about family issues and concerns.

It is our belief that the most successful programs for residents with dementia have been those that have viewed families as clients. One could think of this as **Family-Centered Care**, an approach that views the resident as part of a family unit, and that views the family unit as the focus of care.

Our Own Values about Families

Sometimes there are **racial, ethnic, cultural, or class differences** between families and staff that contribute to communication problems. In these instances, sensitizing staff to family concerns may involve helping staff to examine their own and others' value systems.

It is not uncommon for direct care staff to come from ethnic or racial groups where there is a strong sense of family responsibility for older adults, and a related belief that nursing home or residential care placement is wrong. When staff have been raised with these attitudes, they may have prejudices against the family members of residents, or at least questions or confusion about their own expectations of families.

Helping staff examine their own values about families is not an easy thing to do. Probably the most effective way to change attitudes is constant modeling of behavior and attitudes by supervisors and administrative staff. Thus, the value changes really need to begin at the top of the organization.

We have included an **Imagine** exercise in the *Outline* that you may want to begin with. If you use the **Imagine** exercise:

- Remember there are no right or wrong answers. The point of the exercise is to help staff understand that our attitudes toward families are shaped to some extent by our experiences in our own families. In most families long term care has not necessarily been discussed openly, but there may still be strong beliefs and values conveyed in unspoken ways or by example.
- No one should be forced to volunteer information about this as it is very personal. But it can help staff to see that there are many different experiences in families that lead to many different solutions for long term care.
- The question about families agreeing is an important one; remind staff that the families we work with may be in conflict among themselves.

Another approach to looking at how our own values are shaped is to work through the **Family Values Exercise**, which helps

staff examine how their own families viewed aging, health, and long term care. Helping them to recognize their own beliefs is important as a step toward more understanding and tolerance of family issues.

Another issue that may arise in this session is resentment because employees' families could not afford the services offered by your program, particularly if you work in a program that is expensive and private pay. Our belief is that, should this issue come up, it is important to acknowledge staff frustrations about this, even though we cannot solve this issue. One of the serious gaps in service in our society is dementia programs and residential care that are affordable to middle class and lower income families.

Issues for Families as They Enter the Residential Care Setting

The *Outline* includes a discussion of some of the points about families that we think are important to emphasize. There are a number of ways to increase staff awareness of family issues and concerns. It is often most effective to use a family speaker, a video, a case study, or some combination of those in order to bring family issues to life for staff.

Try using the **Progression of Alzheimer's Disease** from Session 1. You could use either the overheads or the Staff Handout or both. With staff looking at each stage, have them brainstorm together what the issues for families at this stage might be. Included in the *Outline* is a discussion section on issues and concerns of families at different stages of the illness. It is important to remind staff that every family's experience is individual. In this section, we have provided trainer examples following the "Smiths" through the progression of the disease.

There are a number of books that illustrate or discuss family caregiving issues. Family memoirs can be a good way to educate yourself and/or staff about family issues.

There are also a number of books written for professionals about caregiving, which are cited in the *Reference List*. Finally, there are some good books to recommend to families who might wish to read more about dementia.

A Family Speaker

If you use a family speaker for this session, you would ask him or her to **concentrate on how the relative's illness affected the family** as it progressed (instead of focusing on changes in the person with dementia). It can be a very powerful way to help staff understand the perspective of the family. Some things to think about in using family speakers:

- **Spend some time with the family member** to make sure that he or she is comfortable speaking about the situation to a group of staff, and has come to terms with the situation enough to be able to tell the story. Sometimes people are still so angry or grief-stricken that listening to their story is very painful or uncomfortable.
- **Alert the family member** to the fact that speaking about the family situation may be more emotional than he or she expects. Suggest that family speakers think about their obligations for the rest of the day, in case they find this an exhausting experience.
- **Rehearse** some of the things you would like the family member to talk about. We usually write down questions for them to think about ahead of time. Generally a family presentation takes at least twenty minutes and sometimes as much as an hour. It is important to discuss the content, length, and format with the family member ahead of time.

- **Ask them to bring along photographs** of the person and family earlier in life. This helps bring their story to life.
- Be aware that **talking about changes in *their relative* is sometimes easier than talking about their own and other family member reactions.** Because of this, we find that it sometimes works better to interview family members, rather than having them tell their story uninterrupted. The interview format is also a tactful way to control the length of the family member's presentation, if time is limited or the person is a "talker."
- **Suggestions of questions the family member might address** in telling the story from the family perspective:
 - A very brief description (five minutes or less) of the course of the disease. What was your relative like as a person before the onset of dementia? How long has he or she had dementia? How old was he or she when symptoms began? What was he or she doing at that time in life?
 - What was the person's role in the family before the disease? How has each family member had to adjust his/her role as the person declined?
 - A brief description of the course of the disease for the family. How has your relative's illness affected your family? You?
 - How did your family make the decision to move your relative to a residential care setting?
 - What were you and your family feeling as you made this decision and the move took place?
 - What would you say was the hardest time for you as a family member?
 - How do you feel when you visit your relative here?
 - What could staff do to make that an easier time for you?

- What are your concerns about the future for your relative and you?
- Are there strengths you have gained or things you feel good about from your caregiving experience?

Videotapes /DVDs

Using videos or DVDs that show family members coping at different stages of dementia is another way of making the issues real to staff. It serves the same purpose as having a family member speak. We have found that the most effective way to use these is to show 5-10 minute segments and then stop and discuss what we've seen.

It is important, however, to emphasize that a video **only shows one family's experience with dementia** – every person with dementia and every family have their own experience during the course of this disease.

There are a number of videos that tell one family member's story, or show different people at different stages. Several of these videos were discussed in earlier sessions. Any of these could be shown again with discussion emphasizing family issues this time.

From Here to Hope: The Stages of AD: final, middle and early. This video highlights different individuals at different points in the illness. An individual in late stage Alzheimer's disease is the author of *Partial View: An Alzheimer's Journal*; his wife narrates much of this portion. (16 minutes). A man in the middle stage is a musician, still living alone and attending day care; the man's daughter is the primary coordinator of his care and life (21 minutes). A mother in early stage is modeling for her daughter's photography project (17 minutes). Total running time: 77 minutes.

First family in late stage – “*It Hurts Like Hell*”

- What tasks does this man's wife have to do for him now?
- How do you think this disease has changed her life?
- How does she cope with the caregiving experience?
- How could staff be helpful to the caregiver?

Second family in middle stage – “*It Takes a Village*”

- What are some of the challenges for the daughter and friends in this sequence?
- How do you think her father's disease has changed the daughter's view of life?
- How does she cope with the caregiving experience?

Third family in early stage – “*Photographs and Memories*”

- What are some of the challenges for the daughter in this sequence?
- How is the daughter trying to make her mother's life meaningful?
- What are likely to be some of the issues for this family as the woman's disease progresses?

Grace. This video follows Grace through seven years of her life with Alzheimer's disease; we see Grace and Glen at three distinct points in time, when her abilities and needs shift. There are many scenes that can be used to discuss issues for family members, particularly spouses (e.g., the scene in the kitchen early in the video, mealtime in the middle stages, visiting at the foster care home in the late stages).

Total running time: 50 minutes. Many 5-10 minute segments that could be used.

- How has Glen's life changed (at any given point)?
- What are some of the tasks that Glen is doing that Grace might have done when she was well?
- What feelings does Glen express about caregiving for Grace?

Home is Where I Remember Things. The first 14 minute clip on this videotape shows a son living with and caring for his father with Alzheimer's disease. It is a great way to illustrate the 24-hour care demands on families.

- What are some of the tasks the son does for the father?
- How has caregiving changed this son's life?
- What would happen if the father started wandering and getting up a lot at night?

There are many other videos that show family caregiver experiences. Check with your local Alzheimer's Association to see whether they have some videos of caregiver stories that you might be able to use.

Case Studies

Two of the four case studies (**8-A and 9-B**) help staff think about caregiving concerns of adult children and spouses. To use these case studies effectively, follow the suggestions for case studies in Training Staff: Issues to Consider.

Case Study 8-A raises issues about a caregiving spouse whose income is limited. This case study can be used to talk about some of the issues that arise for spouses, when the person with dementia may begin to need full time supervision. This case study may help staff to understand some of the dilemmas faced by spouses as their relatives' dementia progresses.

Case Study 8-B focuses on an adult child who lives long distance from her mother and has had a difficult relationship with her in the past. This case study could be used to help staff understand that families may have a past history that we do not understand. And that there are not always perfect solutions to caregiving dilemmas faced by families.

Creating a Welcoming Atmosphere for Families

The institutional view of families often sets the tone for how families interact with a facility or program. **One of the most important things we, as trainers, can do to improve staff-family relationships is to help create a welcoming atmosphere for families.** Many times staff have never thought about how to greet families, how to provide information to families, or how to give families positive feedback.

Generally we have used exercises of various kinds to attempt to address this issue. The Imagine Walking In exercise is one way of helping staff think about the things that make families feel comfortable or uncomfortable in your setting. Suggested comments and discussion questions are in the Outline. Many times staff need help thinking about what visiting feels like for new families; they may never have thought about how difficult it can be for people who have never been in residential care settings before.

Oftentimes staff are not very practiced at introducing themselves. Staff Handout 9-A: Introducing Yourself was developed for use with a facility whose staff really needed some help with basic introductions. This may be too elementary for some staff, but others will find it helpful to discuss ways to greet families and things to talk about with them. We review these greetings and then sometimes practice introducing ourselves in pairs. In some settings there are class or cultural differences between families and staff in their styles of greeting. Again opening up a discussion of these issues can go a long way toward sensitizing staff and making them feel more comfortable with families.

Family-Staff Reciprocal Training

Another useful exercise to improve staff-family relationships is to **survey both families and staff about things the other group could do to make communication**

better. This can be done in a staff meeting and a family meeting, or by anonymously written suggestions. In one facility, we met with a group of families from the special care unit and brainstormed as a group some of their suggestions for staff. Then we did the same thing at a staff meeting. The suggestions were carefully written up and circulated among the two groups. Below is part of the sample lists developed by the two groups:

Suggestions Staff Members Have For Families

- Please don't think of us as "strangers" caring for your relative. We work here because we like working with older people and we become attached to them. Get to know us as people.
- Give us background information so we can relate to your relative better (followed by examples of what they would like to know).
- Tell us things we can say to reassure or calm your relative.
- Tell us things **not** to say or talk about with your relative.
- Don't believe everything your relative tells you. Check with staff. (And we won't believe everything your relative tells us either!)

Suggestions Families Have for Staff

- Treat my relative as a person. Know that she had a long life and accomplished many things. I would be glad to tell you more about her if you ask.
- Please preserve my relative's dignity by brushing her hair, helping her wash her face and hands, not leaving her with food on her clothes.
- Say hello to me when you see me. Sometimes I feel invisible here.

Many of the problems between families and staff occur because of poor communication or discomfort between them. Another very helpful strategy is to do some training with

families on interacting with staff, but that is beyond the scope of this manual.

Working with Challenging Families

It is very important for staff to understand some of the general issues and emotions that families deal with prior to talking about challenging or “difficult” families. Some staff believe that all families are difficult, and simply helping them understand some of the emotional issues and difficult decisions that families face can increase their tolerance for family members.

However, there **are** some difficult people in the world and some of them are bound to be family members (and residents and staff!). In our experience, the most difficult families for staff are those who are overly critical and demanding. Many of the points in the outline and one of the case studies address this type of family. **As with all other difficult issues addressed in this manual, we believe that a problem-solving approach is the most useful for staff. It helps them feel empowered and gives them practical tools for approaching the problem.**

Exercise: Working with the Difficult Family is another staff exercise to help promote discussion about the kinds of families that are difficult for staff to work with. Using this to lead a discussion can help staff develop concrete ways of responding in situations that may be difficult for them. You may also want to make the point that we all respond differently to people depending on our past experiences. A family member who is viewed as difficult by one staff person may be viewed quite differently by others.

This is another topic area where a role-play may be very useful. Again, it is important to plan it carefully and rehearse it prior to doing it in a staff training session. We have included a **sample staff-family role-play** at the end of this session.

Case Study 8-C also addresses these issues. The goal of this case study is the same as the role-play -- to help staff come up with a list of approaches to use with critical, demanding family members.

Case Study 8-D is an example of a daughter who does not come often. Staff often feel angry with absent family members as well. The goal of this case study is to sensitize staff to some of the reasons why families may not be around much or don't stay long.

Helping staff understand possible reasons for behavior and to develop strategies is very useful. It is also important to acknowledge that some people are simply very difficult and troubled – something we cannot change! All we can change are the ways in which we interact with them and the ways in which they affect us.

Materials on the CD for this session:

Family Values Exercise

Case Studies 8A – 8D

Exercise: Working with the Challenging Family

Staff Handout: Introducing Yourself

Staff Handout: Suggestions of Things to Talk about with Visitors

Staff Handout: Things We Can Do to Make Families Welcome

Session 8: Outline for Trainer

Helping Staff Understand and Respond to Families

Introduction

Many of the people we work with have family members, although some do not. Some have outlived their families or are estranged from their families. Today we are going to think about what life is like for the family member of someone with dementia.

- How many of you have had someone in your family with dementia?
- Would anyone like to share a little about ways in which this changed your family life?
- Did your family reach a point where you had to make a decision about 24 hour supervision of this family member? What was that like?

Institutional View of Families

In some facilities, families play an important part of the daily life. In others they are not very involved or considered very important. **How families are treated by programs will make a big difference in their behavior.** Let's take a moment and think about how families are viewed in our program.

- Do you think of our residents as part of a family unit? Or do you see them as isolated individuals? If you are having difficulty bathing a resident, would you think about consulting the family?
- Do you think families are useful to our residents?
- Do you think we encourage families to participate in care? Or in activities?
- Do you think families know whom to talk to about what? Example: If a family has a question or a concern about their relative's hygiene or meals,

would they know what staff member to talk to?

- Do you feel as though you are encouraged or discouraged from talking with families?
- Do we offer events and opportunities for families to be involved?
- If you were the family member of a resident here how do you think you would feel? Welcome, scared, confused, happy, guilty?

The things we do as a facility will have a large influence on the ways families behave here. **Give an example from above.**

Our Own Values about Families

Each of us has grown up in a family that had certain beliefs and values about what happens to people in our family.

Many times these beliefs and values have not been stated openly, but are still a part of our thinking.

For example, Mr. Brown has Alzheimer's disease. In Mr. Brown's family, it was an unstated belief that you kept your older relatives at home no matter what. When Mrs. Brown died, the kids were faced with deciding whether one of them should quit his job and stay home or place Mr. Brown in a nursing home. Either decision may cause some problems in this family.

Sometimes our values and beliefs about families are not the same as those of our residents' families. This can cause us to feel confused or even angry when we think about the families here. Let's close our eyes briefly and imagine our own family situation.

Trainer: Use the Imagine Exercise or the Family Values Exercise here.

Imagine: Someone in your family has developed Alzheimer's disease. It may be your mother or father, a grandparent, or

a beloved aunt. Take a minute and focus your thoughts on that special person in your family. (pause) You have gradually become the primary caregiver for this relative. At this point it has become unsafe to leave your relative alone, as he or she has wandered away from the house several times and has twice started small fires in the kitchen. The doctor tells you that your relative may live for five or six more years, gradually getting worse. (pause)

You have a lot of confusing feelings. You wonder if you should quit your job and stay with your relative. But can you afford to? You are devastated by what is happening to your relative, but not sure you can live with it twenty-four hours a day. Think for a moment about your family and all the confusion you have about what will happen now.

Open your eyes.

- How did you feel during this exercise? (List feelings people had.)
- What do you think you would do in this situation?

Key points:

- **Some families are able to talk very openly about these issues.** In some, they have planned together what they will do in the event of an illness such as Alzheimer's disease.
- **In other families, the desires are clear without discussion.** For example, an older father might ask his kids to promise never to put him in a nursing home.
- **In other families there is no discussion,** but sometimes there are examples, such as a grandparent with Alzheimer's coming to live with you.
- Does your family talk openly about the future? Have there been discussions about what would happen if someone became very ill?

Key point:

In some families there is disagreement about how to handle care.

In one family the three sisters totally disagreed on how to handle care of their mother with Alzheimer's disease. The daughter who lived close felt that she could not handle the care alone and wanted to move her mom to a more supervised setting. The two daughters who lived farther away were totally opposed to moving their mom.

- Do you think your family would all be in agreement?

Debriefing comments about values:

- **There are no right or wrong answers to this exercise.** This is just to help each of us think about how our attitudes toward families here have been shaped by our own family experience.
- We can see from doing this exercise together, that **there are a lot of differences in families.** (Or a lot of similarities in your families.) People who come from different religions, different neighborhoods, different backgrounds have often been raised with different beliefs about how to care for ill family members.
- Also, several of you felt that there would not necessarily be agreement among family members in your family. This is true of many families and of some of the families in our program. It is normal but can be tricky at times for us as staff.
- **Sometimes it is very hard to get past our own beliefs** and understand that other people have different experiences and beliefs. As we interact with family members here, let us all try to remember this.

Issues for Families as They Enter the Residential Care Setting

Definition of caregiver or care partner:

These are terms we often use to describe family members who have provided care to the person with dementia. Also, those who provide care in residential settings are often called caregivers. But **issues for family caregivers and professional caregivers may be very different.**

The **role of a family caregiver of someone with dementia occurs slowly**, because the disease develops gradually. Sometimes family members may be acting as caregivers, but not think of themselves that way.

Most family members will tell you that the decision to move their relative here was **one of the hardest decisions they ever made.** At the time when a resident with dementia moves into our program, families have already been dealing with the disease for a long time.

Most family members still consider themselves caregivers after their relative moves. The caregiving role is different but can still be stressful for families. Most families consider an important part of their role is to make sure their relative gets the best care possible -- this is sometimes where we run into conflict with families.

The Family Experience in Dementia

Trainer: Show a **video** here, or **Family speaker** here, or use the **Progression of Symptoms** handout and powerpoint slides here from Session 1. There are also powerpoint slides in this session that match the outline of issues below.

Alzheimer's Disease – Progression of Symptoms:

The Impact on the Family

Although this is for AD, the symptoms are similar enough in other dementias to use this to talk about family experiences in general.

Reminder: This is just a broad guideline – every individual and family with dementia experience the disease differently.

First / Early Stage

As we look at the First / Early Stage, what might be some of the issues, concerns, and feelings of families?

- **Uncertainty.** Prior to diagnosis, families often don't know what is happening. Is the person depressed? Secretly drinking? Angry at her spouse? Mr. Smith finds that his wife can remember well some days. Other days she is very confused and forgetful. Every morning when he wakes up he wonders what the day will be like.
- **Fear of what the future holds.** Mr. Smith wonders if he will be able to manage. Will his wife become "violent," as he's heard some people with dementia do? Will she become incontinent? How will she be next year?
- **Denial.** Not wanting to face what is happening now; not wanting to think about the future. **Note: Denial is not necessarily negative.** If it is not putting anyone at risk, it may be a good coping mechanism. However, if it prevents medical assessment or if it means the person with dementia is unsafe, then it is a problem.
- **Frustration.** Mrs. Smith is told by her husband that their son will be visiting. She asks about the visit repeatedly because of memory loss and then is surprised when he shows up. Mr. Smith feels frustrated.
- **Feeling like the person is not trying hard enough.** Mr. Smith sometimes feels like Mrs. Smith isn't trying. "On Monday she was able to cook dinner. So why can't she on Tuesday? I think she's just being lazy or not concentrating enough."

- **Angry.** Families often feel angry that this is happening. Sometimes it translates into anger and frustration at the person with dementia, sometimes it is anger at God, sometimes it is just plain angry feelings at everyone around.
- **Not knowing what to do.** Families frequently ask, “Am I doing the right thing?” Often there are no rights and wrongs, no clear ways to assess safety in the early stages.
- **Grief and sadness.** It is heartbreaking to have someone you love develop dementia. For most family members, there are periods of grief throughout the course of the illness.

Common Concerns in the Early Stage:

- **Driving** – whether the person is safe to keep driving or not.
- **Safety issues** – cooking, running the lawn mower, using tools or sharp knives, continuation of hobbies that may be dangerous, such as hunting, hiking, or running.
- **Legal planning** – important for families to do this early while the person with dementia can still participate.
- **What to tell the person** about their diagnosis.
- **How to help the person** be as independent as possible.
- **Having to take over more and more of the person's responsibilities.**
- Now the Smiths are grocery shopping together. Mr. Smith is trying to learn to cook a few things. He has begun paying the bills after they received a shut-off notice from the gas company. All those tasks used to be Mrs. Smith's job.

Second / Middle Stage

As we look at the Second / Middle Stage, what might be some of the issues, concerns, and feelings of families?

- Many of the same issues and feelings from early stage continue: **grief, sadness, uncertainty, anger, frustration.**
- **Feeling helpless.** It is very painful for families to watch a member becoming more confused, more forgetful, and not be able to stop it.
- **Overwhelmed.** As the disease progresses, this is a common feeling of caregivers. Mrs. Smith is up and down all night sometimes. She also has begun following Mr. Smith everywhere he goes in the house. When he is not in sight, she becomes anxious and panicky. Mr. Smith describes himself as feeling overwhelmed by the care and responsibility.
- **Exhausted.** Remember that some caregivers may have been providing 24-hour care by themselves for four, five, or even ten years by this point.
- **Fear** about what to do if they can no longer manage. Mr. Smith says, “What if something happens to me? How will my wife be cared for? Or, what if she stops walking – how will I manage then?”
- **Resistant to help.** Many families believe that it is their responsibility to take care of their own family members privately, by themselves. They do not want help, even though they may need it. This can often be frustrating to other family members who may want to help and see the need for more help. The Smith's daughter lives 500 miles away. She cannot easily be there to help, but would like to pay for a home health aide to come in. Mr. Smith refuses. The daughter feels frustrated and helpless, because she knows he needs more help.
- **Embarrassed** by things the relative with dementia does. When they eat in a restaurant now, Mrs. Smith often

picks up salad and peas and meat with her hands, because she no longer remembers how to use a fork. Mr. Smith feels very embarrassed when she does this in public. Last week in a restaurant, Mrs. Smith tried to sit down with a family she didn't know, because she was attracted to their baby.

- **Isolated.** Many times family caregivers become very isolated during the middle stages of dementia as it becomes harder to take their relatives places. Mr. Smith has lost touch with his friends from the Rotary Club. He has not been able to attend meetings for more than a year.
- **Conflicting responsibilities.** Often family caregivers have to make difficult choices. The Smiths' daughter thinks maybe she should quit her job and move back with her parents to help. Or, a spouse needs to keep working, but also needs to be providing care. Or, an adult child is spending so much time helping her mother that her husband and children feel neglected.
- **Coping with behaviors that may be difficult.** This is the stage where some of the more troubling behaviors may appear (though not necessarily). Caregivers may have to cope with wandering or angry outbursts or delusions.

Common Concerns in the Middle Stage:

- At what point the person is **no longer safe alone** in the house.
- **How to provide 24 hour/day supervision.**
- **How to communicate** when language skills are decreasing.
- **Finding activities** the person can still do.
- **Having to take over more of the relative's tasks.** Mr. Smith now has to do all of the cooking, the laundry, although she can still fold clothes. He does the housekeeping, the shopping,

managing appointments, yard and house maintenance, and helps Mrs. Smith with dressing and bathing.

Third / Late Stage

As we look at the Third / Late Stage, what might be some of the issues, concerns, and feelings of families?

- Many of the feelings from earlier continue: **grief, sadness, helplessness, uncertainty, denial, exhaustion**, especially if the person is still at home.
- **Grief, because of no longer being recognized.** This does not always happen, but it is devastating when a spouse or parent no longer knows who you are. Some family members may tell staff that the resident knows them, when you aren't so sure. There is nothing to be gained by questioning this.
- **Common feelings about a relative's move into long term care:**
 - **Grief.** Placement is a sign that the person really has changed significantly.
 - **Feelings of failure.** Many families feel that they should have been able to manage at home, even though it may have become impossible. And if it is a family where there is conflict, or where there have been promises about no nursing home, the feelings of failure may be very strong. Mr. Smith feels he has failed as a husband. He is angry at his daughter for pressuring him to move his wife, even though he became ill himself.
 - **Anger that it came to this.** Caregivers may be angry at the disease but direct their anger toward staff.
 - **"No one can provide as good care as I did."** *Example:* Mr. Smith tends to be critical of the care his

wife gets. He feels like he did a better job and no one can do it as well. It is true that because families can provide one-to-one care, it may sometimes be better. Usually acknowledging this is helpful, "I know that you gave your wife wonderful care, Mr. Smith. We do our best, but we can never give the kind of loving total care that you provided."

- **Relief.** Some families may feel relief that they are no longer the sole caregiver but feel guilty at the same time because they have needed others now to help with the care. It is often a very confusing time.
- **Guilt.** This is often the most difficult emotional reaction to a relative's move. For some families the guilt never ends, and it may lead to anger or to staying away. Guilt comes from feeling that things might have been different, if only.... As staff, we can listen and reassure that the family made the choice they had to make at that time.
- **"I did the best I could."** A feeling that staff should reinforce. Families will feel comforted if their long caregiving struggle is acknowledged.
- **"I still want to be involved."** Helping families think about ways to be involved in their relative's care or in the life of the program is very important. Help them to volunteer with activities, help with special events, speak at staff trainings.

Common Concerns in the Late Stage:

- **Worries about money** (care is expensive!).
- **What does my relative feel?**
- **Will their relative have to move again?**

End / Dying Stage

Common Concerns in the End Stage:

- **End of life decisions.**
- **What will happen after the resident dies?** In some cases spouses or other family members have built their daily lives around the care of their relative.
- **How to make the person's last months comfortable.**
- **How to say good-by.**
- **Confused feelings about the person's approaching death.** Mr. Smith wants to do everything possible to keep Mrs. Smith alive, because he still takes pleasure and comfort from her, even though she is very impaired. He denies that she may be approaching death, even though she has stopped eating. On the other hand, Mrs. Carr feels like it is time for her husband to die. He has not been able to feed or dress himself for two years; he stopped walking four months ago. She feels guilty that she thinks he should die, but also feels that he has no quality of life left.

The Move to Residential Care

What might be some of the **common reasons for moving a relative with dementia into residential care?**

- Physical health of the caregiver.
- Physical health of the person with dementia.
- Person with dementia loses the ability to walk and becomes difficult to transfer.
- Behaviors of the person with dementia. Usually it is a combination of behaviors that become overwhelming, such as 24 hour wandering, agitation, incontinence, loss of recognition of caregiver and home.
- Lack of social supports from other family or friends.
- Pressure from family and physician.

- Finances (residential care may be cheaper than 24 hour care at home).
- Emotional distress or depression that makes the caregiver unable to provide care.

The Benefits of Caregiving

What might be some of the positive things for a family member from the caregiving process? **Trainer:** Give examples as staff come up with benefits.

- A chance to pay back love and nurturing.
- Honoring one's wedding vows.
- Honoring one's responsibility to a parent.
- Learning new tasks (e.g., a male spouse learns to cook; a female spouse learns to handle finances).
- Continued companionship (especially for spouses).
- An opportunity to resolve old issues with the relative with dementia.
- A chance to develop a closer relationship.
- Knowing that the caregiving is being done well.

Summary Comments:

- **A person with dementia vs. a person with a history.** When staff look at the resident, they tend to see a person with dementia. When the family looks at the resident, they see a person with a whole history, set of relationships, and emotional involvement with them. They see a mother, sister, grandmother, aunt, etc. This gives families a very different perspective and sometimes can lead to unrealistic expectations.
- **The family and the resident have lived a whole life together before we met them.** We will never know all the complex dynamics that have occurred in this family. It is important not to judge what we do not understand.

- **Families often feel a lot of grief and guilt about their relative living away from home.** Many of the behaviors we see in families may come from these very difficult feelings. Families usually love the person with dementia and want life to be as perfect for her as possible. They may become frustrated with the realities of life in our programs and facilities.

Making Families Feel Welcome

Together we are going to think about how families might be feeling when they come into our facility. Close your eyes for a moment and let's think together what it might feel like to come to our place for the first time.

Imagine Exercise

Trainer: This exercise may be even more effective if you take the staff to the front door of the facility and have them actually experience the sounds, sights, smells, etc.

Imagine Walking In to our facility for the very first time as a family member. As you enter, look around you as you walk in the front door. What are the first things you see? How does this make you feel? Let's pause for a moment – keep your eyes closed – and each of us think about what we see and how we feel. (pause)

- Now listen. What do you hear as you walk in the front door for the first time? How does that make you feel? (pause)
- What do you smell? Does it smell good? Are there unfamiliar smells? Or cleaning fluid smells? Urine? How do you feel? (pause)
- Who is the first person you will see? Does this person greet you? Do you feel welcomed? Do you feel scared? What do you wish would happen? (pause)

- Now open your eyes and let us talk about the experience.
 - What are some of the feelings you experienced?
 - What were the first things you saw?
 - What were the first things you heard?
 - What did you smell?
 - Would this be a pleasant experience, do you think? A scary one?
 - Did you feel welcome?

Staff Handout: Introducing Yourself. Hand out and discuss together.

Things We Can Do to Make Families Feel Welcome

What are some things we can do individually or as a facility to make families feel welcome?

- **Be friendly and welcoming.** Call family members by name. “Hello, Mrs. Green.”
- **Wave to them.**
- **Have staff nametags that are large and clear** (for both residents and families).
- **Make sure families know who to go to.** Many times families have no idea of the appropriate staff member to talk with about a problem or concern.
- **Give families regular information** about their relatives, especially positive things that have happened.
- **Provide a bulletin board** just for families, a place where staff and families can communicate with each other.
- **Encourage families to attend care conferences. And make them “user friendly” for families.** Some care conferences are structured in ways that discourage families from attending, such as, not enough notice given, scheduled in the middle of the day,

led in a way that is intimidating to families, not enough time allowed, nothing changes, concerns expressed by families are not followed up on.

- **Encourage families to volunteer.**
- **Encourage families to join activities.** Many times families do not know what to do when they visit. Developing activities that they are encouraged to attend with their relatives can be very helpful.
- **Encourage families to make photo albums,** write biographies, or provide labeled photographs to help staff become more aware of the residents’ past lives. Families feel that staff care when they take this kind of interest.
- **Offer family education and support groups.**

Working with Challenging Families

Introductory comments

All of us have had to deal with families who were difficult. But different things may make each of us uncomfortable or upset.

Reminder: There are difficult people in the world, and there are difficult people at our place too! **Some of them are family members, some of them are staff, some of them are residents.** We don’t always understand the reasons for their behavior, but we can try. We may not be able to change their behavior, but we can change our response to it.

Use **Exercise: Working with the Challenging Family** here. Fill out individually and discuss as a group.

Debriefing comments:

It is helpful to understand more about our responses to families. As with residents, some of us will find one person difficult, while others will work well with him or her.

If we can learn to think of strategies for responding to the person, generally we will handle the relationship better.

Critical, Demanding Families

Do a **role-play** here, or
Use **Case Study 8-C**.

What are some reasons a family member might behave in a critical, demanding way?

- **Guilt** about not being the primary caregiver anymore.
- **Angry** about the disease process. Angry about having the family member live in a facility. Angry person in general.
- **A perfectionist personality**, that needs to have everything done “just so.”
- **Knows what good care should be.** Maybe some of the complaints are legitimate.
- **Frustrated.** Perhaps the family member has asked for something to be done a number of times and it still is not being done.
- **Doesn't understand how things work here.** Perhaps the family member doesn't realize that their relative was just toileted. Or that the philosophy is not to force someone to bathe against her will.
- **Doesn't have all the information.** Maybe some new physician order has been implemented and the family doesn't know about it.
- **Uncomfortable** in the setting. Some people act angry and defensive when they are uncomfortable.
- **Had a bad day.** The family member may have things happening in the rest of her life that we know nothing about, but that are causing great stress.
- **The person's appearance** may be upsetting to the family member: what the person is wearing, how she looks, whether her face has been washed, her hair combed, dirty clothing removed,

can all have a large effect on the way a family member feels and acts.

- **Feeling helpless.** The family member may be trying to make and person and her life better. Knowing that they can't change the course of the disease, sometimes families feel desperate to influence the quality of life.

Now that we've thought about why a family member may exhibit a critical or demanding communication style, let's come up with a list of things we can try with family members like this. What are some things you've found that might help with this problem?

- **Make the person feel welcome.**
- **Keep the family member informed.** Try to greet her before she reaches her family member's room. If there is something she may be upset about, try to prepare her. “Mrs. Brown, I just wanted to tell you that your mother is wet. I just discovered it and am on my way to change her.”
- **Develop a personal relationship.** Learn the family member's name and use it. Get to know her. Compliment her on the fact that she is so involved and caring.
- **Be sympathetic** if you can. Sympathy and listening are often enough to make an upset family member feel better.
- **Don't argue.** Being defensive or arguing never helps. Usually it just makes an angry person angrier.

Trainer: The following points differ from facility to facility. Discuss your organization's policies about staff-family communication. Amend these points to fit your organization.

- **Share information about the resident.** Tell the family member what has been going on with her relative. Be sure to include some positive things, but keep her informed of changes as well.

- **Allow the family member to vent.**
Sometimes they just need someone to listen.
- **Offer to correct the problem now.**
Example: “I’m sorry your mother hasn’t been bathed. We’ve been having a lot of trouble. Maybe you would like to show me an approach that you’ve found that works.”
- **Suggest the complaint procedure.**
If you can’t fix the problem, tell the family member whom they should talk to. Often families don’t know who to turn to for what.

The Absent Family Member

Use Case Study 8-D here.

What are some reasons that a family member might not visit often or stay long?

- **Too difficult emotionally.** Some family members report “crying all the way home” after every visit. For some, it is just too difficult to see their loved one in this condition.
- **Other things going on in life.**
Generally we do not know much about family members’ lives outside of our program. There may be other family health problems or traumas that are keeping the person away.
- **Distance.** Sometimes families have to choose a program or facility that is far away from their home. It may be difficult for them to get there often.
- **Never close to the person.** We never know the whole story of a family. Perhaps there was a difficult relationship between the resident and family members. Perhaps they were never close.
- **Don't know what to do.** For some people, visiting their relatives with dementia is extremely difficult. They don’t know what to say or do and the time drags by.

- **Too difficult or painful to leave.**
Families often find it very difficult to say good-bye. Perhaps their relative follows them and begs to go home, or maybe saying good-bye just reinforces how permanent the changes are.
- **Uncomfortable in the facility.**
Sometimes family members are very distressed by the sounds, smells, and sights in a dementia unit or nursing home. It may take a lot of courage for some to come at all.

Now that we’ve thought of some reasons why a family member may be absent, let’s think about how we can help. What are some things we might do to help the “absent” family member?

- **Ask social services staff to try to find out why the person doesn’t come often.**
The more we understand, the more we can help.
- **Don't judge.** We never know the whole story. If we are judgemental, our tone of voice will communicate that and distance the family member even further.
- **Make the person feel welcome.**
(Discussed earlier.)
- **Stay in contact** even if the person isn’t coming. Phone calls and letters may help the family member feel connected and more comfortable when she does come.
- **Help make visits easier.** (Discussed earlier.)
- **Invite the family member for special occasions.**
- **Listen, accept, and support them.**

SLIPSHEET

Session 9: Caring for Yourself So You Can Care for Others

Chris Curtin

Interactive Training Strategies

- Discussion questions offer a framework for discussion on the self-care topics.
- Role-plays between staff about the value of direct care work and to demonstrate good listening skills.
- Exercises using handouts that can be completed individually, in pairs or small groups.

SESSION 9

SUGGESTIONS FOR TRAINERS

Caring for Yourself so You Can Care for Others

The goals of this session are:

- To identify personal issues or attitudes that may impact your caring relationships.
- To identify appropriate methods of preventing and coping with stress and burnout.
- To identify personal ways of coping with grief and loss issues.
- To name effective ways to interact with employers and co-workers regarding differences in philosophy or implementation of care practices, with a focus on what is best for the person with dementia.

Introduction

In 2006, the document *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers* was published (Michigan Dementia Coalition, 2006). One of the competencies that was identified by the Michigan Dementia Coalition is Direct Care Worker Self-Care. This session was developed to address that competency. Although direct care workers nurture others, they often do not care for themselves.

This session is divided into several training units:

- Personal issues and attitudes
- Communication tools
- Recognizing and preventing stress and burn-out
- Resources on self-care.

Each training unit has a series of interactive activities to help direct care workers reflect on their own situations and practice skills for better self-care. The activities are designed to honor what direct care workers already know and encourage them to build on that knowledge. All handouts are on the CD.

Personal Issues and Attitudes

This section is about how our personal histories may bring about strong personal reactions to our work.

Activity 1 is a personal preferences continuum. The continuum is used to show personal differences visually. One person stands at one end of the room and another at the other end. Statements are read that show a personal preference, such as being an introvert or extrovert. The participants are asked to go to the end that is most like them. Some will want to be in the middle. After each set of statements are read and all the participants move, take time to hear from people at both ends and in the middle. The activity is meant to help us understand that people are different and we can tolerate differences in each other. Not everyone has to be the same. We can learn about the customs or people that are different so we can provide care with respect.

There is an optional small group debriefing after the continuum exercise. This allows the participants to process their own thoughts and promote self-reflection and sharing.

Activity 2 helps staff examine situations that may be stress-inducing triggers for them. We all have personal triggers that may affect our ability to provide care. The handout lists a number of situations a worker may encounter when caring for a person with dementia. Knowing ourselves helps us to be prepared. We also see triggers in persons with dementia. Awareness can help us to avoid challenging situations.

Activity 3 is a role-play of a direct care worker and her friend. It is meant to address the lack of respect and stigma of working in long term care. The role-play is read by two participants. Ask them how they felt afterward. The set of questions for brainstorming helps to bring out into the open the stigmas and lack of respect some workers have encountered.

Activity 4, understanding needs and motivations, includes two handouts. The first one utilizes self-reflection of why this type of job was chosen, and what strengths the workers bring to the job. It also explores the pitfalls of being a nurturing person. The issue of caring for others and not caring for yourself is addressed. The final question is a way of honoring the worker in asking them to describe the non-monetary rewards of their job.

The second handout is a list of needs and motivations of direct care workers. They are encouraged to look over the list and check the ones that they feel are true for them.

With each handout, the workers pair off and share with a partner what is on their list. This time of sharing is very important because it allows everyone to process their thoughts and find common ground.

The final part of this activity addresses the desire to solve everyone's problems. This is an opportunity to think about the effect on the other person. When we rush in to solve a problem, we are really telling the person that we do not trust them to figure it out. Asking them questions about what they have thought of and expressing trust that they will work it out shows respect. People are really ready to hear advice when they ask for it. This is a common issue with nurturing people and can bring out interesting discussion.

Communication Tools

The purpose of this training unit is to stress the importance of active listening to encourage communication. The skills of paraphrasing, asking clarifying questions and pull back – a term for pulling back rather than allowing one's emotions to get out of hand – are demonstrated. The content for this section is based on the curriculum of the Peer Mentoring Program and the Coaching Supervision curriculum developed by PHI (formerly Paraprofessional Healthcare Institute). This curriculum can be found online at directcareclearinghouse.org.

These skills require practice and time to develop. Many find that paraphrasing is difficult to master. **Activities 5 and 6** are exercises to help staff practice active listening and communication skills. Participants may find that when they try these skills, they work well for spouses, children, co-workers as well as those they care for. The handout Know Your Triggers can be reviewed for situations that may require pull back, a term for. Discussion of which strategies could be used for these situations is done in a brainstorming session.

Recognizing and Preventing Stress and Burnout

Activity 7 is brainstorming causes of stress. Using a flip chart, the participants are encouraged to list some causes of stress. Possible answers are listed in the curriculum.

The handout, Warning Signs of Stress, allows the participant to review different signs and circle the ones they see in themselves and in others. The participants work in pairs to increase participation. Burnout is defined as stress that is not coped with effectively. Stages of burnout are shown.

Activity 8 looks at stressful interactions in caring for a person with dementia. The purpose is to have the participants reflect on their past experience in dementia care and how they coped with a stressful situation. Questions are placed on the flip chart for them to answer. Time is allowed for them to write their answers, share with another and then group discussion.

Activity 9 addresses self-care. Some have the idea that a direct care worker cannot care for others and still have time to care for themselves. The word selfish is written on the flip chart and participants are asked to define selfish. They may say that it is putting your own self first without regard for others. The sentence is then completed on the flip chart to say 'Self-care is Selfish.' A group discussion explores if this is true or false. Why do nurturing people put their needs last? Encourage all to participate.

The handout, Coping with Stress, is a checklist, listing a number of options for dealing with stress. The participants fill it out and then share their answers with a partner. The handout also asks about the balance of mind, body and spirit.

Activity 10 is telling the story of someone special, part of a discussion about coping with loss and grief. The losses that both caregivers the person with dementia experience are discussed. Through the discussion of someone memorable who has died or someone difficult to care for, staff can remember feelings connected with the loss. How did staff get closure? The rituals and ceremonies that workers perform to remember someone are discussed. Finally, tips for coping with grief and loss are offered.

Resources on Self-Care

These resources are recommended for staff who would like to practice some of the self-care techniques discussed in this session.

CD: *The art of Meditation Four Classic Meditative Techniques Adapted for Modern Life*, Daniel Goleman, Ph.D.

Videos: *The Joy of Stress: How to Prevent Hardening of the Attitude* and *Humor your Stress: Jest for the fun of it*, both by Loretta LaRoche. Available at www.wgbh.org.

Some of the information for this chapter is adapted from training programs developed by Community Services Network, Traverse City, MI

Materials on the CD for this session:

Activity 2: Know Your Triggers

Activity 3: Role-Play

Activity 4: The Direct Care Worker as a Nurturing Person

Activity 4: Needs and Motivations of Direct Care Workers

Activity 6: Communication Tools Make a Difference

Activity 7: Warning Signs of Stress for Direct Care Workers

Activity 9: Coping with Stress

SESSION 9

OUTLINE FOR TRAINERS

Caring for Yourself so You Can Care for Others

Personal issues and attitudes

Key Points

- **As direct care workers, our personal issues and attitudes may affect our ability to provide care.** Each of us comes with a personal history. We may be uncomfortable with certain people or things sometimes a emotional reaction without logical explanation.
- **We all have feelings and can have strong personal responses to certain situations.** There is a lot of stress in our jobs. Day after day, we are responsible for other human beings who have many needs. Our ability to manage our reactions to stressful situations is critical when caring for a person with dementia.

Activity 1: Personal preference continuum

Learning outcomes

- Describe the basic dimensions of personal style and how they relate to our tolerance for others who are different.
- Describe how our own experience and history affect how we perceive others.
- Identify characteristics about which you have uncomfortable or negative feelings
- Explain how being aware of differences in style and culture can have a positive impact in how care is provided.

Instructions

Find an area in the room where people can stand and spread out. One trainer will stand at one end of the room and one trainer at the other end. Each will read statements and the participants should be

instructed to move closer to the person reading the statement that best fits them. Ask for comments from people who are close to the ends of the continuum and to those in the middle.

Continuum statements

Person A

Extrovert

Big picture, visionary

Feeler- emotions play a big part

Present oriented- wants to think about now

Like to get up really early and go

Run late getting places

Like to travel and see new places

Willing to try any exotic food

Enjoys riding motorcycles

Loves to watch sports on TV

Grew up in culturally diverse setting

Person B

Introvert

Has to have all the details

Thinker- wants to think things out

Future oriented- looking past now

Wants to sleep in and stay up late

Always on time or early

Stay in state, camping, family

Prefer familiar comfort foods

Cars are just fine, a lot more safe

Do not like to watch sports

Few cultural differences in my town

Conclusion: We have seen how different we all are and know we are different from many of our clients or residents. If people or customs are different than ours, we make the commitment to learn more about them to provide the best care.

Optional: Small group debriefing

After the participants take their seats, ask them to share with each other what aspects of direct care affect them emotionally. Then have each person share with the person next to them a time when they felt different

and how it affected them. Allow ten minutes for discussion, ask the group if they have anything they want to share.

Conclusion: We have learned more about what affects us, who we are and why we react to certain situations. It is natural to be uncomfortable or feel anxious if we are going to care for someone who is very different from us. Our responsibility is to be open to learning about the person, their culture and how to interact respectfully with the family.

Activity 2: Know your triggers

Learning outcomes

- Explain how personal triggers may affect our ability to provide care.
- Describe how our own history and personality may contribute to strong personal feelings in certain situations.

Instructions

Give handout, Know Your Triggers, and have each person fill it out. If time allows before group discussion, have the participants talk with each other at the table or in pairs. Allow time for debriefing as whole group to discuss common themes.

Conclusion: Knowing what situations are personal triggers for you can help you avoid situations that are challenging.

Activity 3: Role-play of direct care worker and friend

Learning outcomes

- Describe personal experiences related to what happens in the role-play.
- Describe the challenges of others not valuing your work in long term care.
- Identify stigmas that exist in working in long term care.

Instructions

This role-play illustrates the lack of understanding of how challenging and rewarding a job in long term care can be. The purpose is to identify feelings and stigmas that exist for direct care workers.

Ask for two volunteers to read the role-play. Give each a copy of the role-play. Tell them that they do not have to stop at the end of the written role-play, but may continue to improvise if they want to.

Role-play

Sarah sees Marion going into the grocery store.

Sarah: Hi Marion, I haven't seen you in a long time. What have you been up to?

Marion (in an apologetic tone) " I work at Holly Home

Care now and I take care of people with dementia. I'm just a direct care worker."

Sarah: "That must be so rewarding, I guess. I hear there is not much money in that type of work. You don't have to get much training either."

Marion: "There are a lot of things to learn. I really like working with people with dementia, they require special care and..."

Sarah: "I don't know how you can do it. I only want to work with normal people."

Marion: "They *are* normal people. They have memory loss but they still are..."

Sarah: "Look, I have to go now. Good luck".

Debrief

Ask the participants if anything like this ever happened to them or someone they know.

Do you think there is less status and recognition in a job such as yours?

The following activity will help us to think more about why we are in the business of caring for others.

Key Points

- Our personal history includes how we have been affected by things in the past that have shaped who we are.

What your life was like when you were a child, your personal struggles, your siblings and who your parents are all affect who you are today.

- We have learned behaviors from watching how our parents and others communicated with each other, solved problems and how they dealt with stress.

Activity 4: Understanding needs and motivations

Learning outcomes

- Describe how our personal history affects our ability to provide care.
- Identify needs and motivations that we have as helpers.

Instructions

Give Handout 2, The Direct Care Worker as a Nurturing Person, to participants and ask them to fill it out. Allow about five to eight minutes. Then ask them to turn to their partner and share what they have written. After they have discussed their answers for about five minutes, write comments on the flip chart.

Then give out Handout 3, Needs and Motivations of Direct Care Workers. Allow five minutes for the participants to complete the handout. Write the categories from the handout on the flip chart. Go around the group and have each person tell what they checked off and why. Put a check mark in front of the item on the flip chart. Identify common themes.

Problem solving- Is it really helpful to solve other people's problems?

Go back to the last item on the list of the handout – the need to provide answers. Talk about the concept of a nurturing person wanting to solve other people's problems. When we rush to solve, we are telling that person that we do not trust that they have the ability to solve the problem. If we use good communication skills and take the time, we can offer the valuable gift of listening as someone talks through their concerns. Asking what the person has

already thought of as solutions tells them that you have faith that they will be able to solve their own problem. Jumping in to solve a problem may make us feel good, but it diminishes the other person.

Communication Tools Make the Difference

Key Points

- **Self-management means understanding ourselves and our triggers.** It also means having skills to improve our interactions with others. We communicate daily with family members, friends, co-workers and people with dementia and others. We can reduce stress and have more meaningful interactions by learning a few important skills.
- **Active listening means listening with one's full attention.** Paying full attention to the speaker, using eye contact and leaning forward shows we are listening. We are able to recall more of what is being said. When we really listen, the person feels that we care about them and what they are saying.

Activity 5: Practicing listening skills

Learning outcomes

- Describe the importance of active listening skills.
- Explain how poor listening skills hurt good communication.

Demonstration role-play: Active listening and poor listening

Have one trainer tell a personal story to a second trainer, who uses poor listening skills. This may include looking at a watch or a cell phone, playing with some papers or not making eye contact. Allow about two minutes for the role-play.

Discussion questions

What did you see happening in this role play?

Have the person who was trying to tell the story describe how they felt.

Ask the other person how much they heard. Repeat the role-play, showing good communication skills. Repeat discussion questions.

Practicing good listening skills

Instructions

Divide the participants into pairs. Have them practice poor communication skills first with each other and then repeat with good communication skills. Then have the couples switch roles and repeat. Having the groups switch roles is important so that everyone can experience the feeling of not being listened to.

Conclusion

We have all found that it feels good to be listened to. Active listening is how we come to care about and understand others. It creates safety for the other person because we show that we care and are interested in their struggles.

Activity 6: Paraphrasing, clarifying questions and pull back

Learning outcomes

- Explain paraphrasing and the role it plays in effective communication.
- Define the use of open-ended and curious questions to learn more information.

Key Points

- Sometimes we think we understand what someone is trying to say. We may be right, or we may be making an assumption. We decide that we know what another person is thinking.
- **Paraphrasing restates in your own words what the other person has said.** It helps to clarify communication. It is reflecting back to the person what they have said, using different words. If you are right, it shows that you are listening. If you are wrong, you have just cleared up an assumption.
- Paraphrasing helps people feel like you are listening. False assumptions and errors can be cleared up right away.

Planning to paraphrase requires that a person focus on what the person is saying. It keeps the conversation centered on the other person. The person feels free to keep talking and keep exploring their situations or feelings.

Examples

“It sounds like you are concerned about Mrs. Smith when she is smoking and burning holes in the carpet.”

“What I think I am hearing is that you are having a difficult time when giving Mr. Rogers a bath.”

“So am I hearing you correctly that you are feeling ill and you’d like me to fill in for you?”

Key Points

- **Questions help to clarify and expand information.** It is important not to challenge or blame someone.
- **Clarifying questions** also promotes good communication. Clarifying questions help us to get more information about what the speaker is telling us.
- **Questions that begin with who, what, when and how** produce more information than yes/no questions.
- **Open-ended questions** elicit more information than yes/no questions. They allow the person to expand on what they are saying. They often begin with how, what, or why.
- **Curious questions** help you to probe deeper to get more information.

Examples

I am curious about Mrs. Clark and her reaction to the new medication she is taking.

How did you feel when Mr. Larson tried to kick you when you were putting on his shoes? Compare this to: Were you angry when Mr. Larson tried to kick you?

When you made the decision to call the supervisor, what were you thinking would happen?

Practice the skills of paraphrasing and open-ended questions using Handout 4.

Key Points

- We have talked about personal preferences and knowing our triggers. Our area of work can be very stressful. We can have strong personal responses to situations.
- **Pull back is a technique that helps to manage our feelings in stressful situations.** Pull back means stopping to think before allowing ourselves to lose emotional control. We can put those emotions aside and then deal with the situation. Pull back helps you to stay aware of your emotions. It allows you to remain present with the other person without reacting. By practicing active listening, and using paraphrasing and questions, we can focus on what the person is saying.
- **Use pull back in two ways:**
 - If you know there is the possibility of a difficult interaction, decide what the pull back strategy will be ahead of time, or
 - Pull back during an emotional response and set the feeling aside to listen. Coach yourself silently to keep your emotions under control. Some people count to ten or use a phrase to remember to control their emotions.

Example

A direct care worker was accused by a person with dementia of stealing her purse. The staff member used self-talk to remind herself that the person had a disease and not to take the accusation personally.

Practice: Have participants look at their first handout, **Knowing your Triggers**. Ask

what pull back strategy they might use for the situations on the handout that they had identified.

Conclusion

By using good listening skills, paraphrasing, questions and pull back, we can have more effective communication. We can use these skills to better communicate with the people we work with, our families and the persons we care for. These skills can help us when we interact with our supervisors and co-workers. Sometimes when we are caring for persons with dementia, we encounter differences in philosophy or care practices. We can use our communication skills to help focus on what is best for the person with dementia in a way that is not blaming or confrontational.

Recognizing and Preventing Stress and Burnout

Key Points

- **Stress is what you feel when you have to handle more that you are used to handling.** Stress is subjective. What makes one person strained may not bother another.
- **Our bodies react to stress.** The heart rate increases, and breathing becomes shallow and rapid. Stress can produce physical pain when our muscles get tight; we get a headache, backache or sore shoulders. Anxiety and worry affect the stomach, causing mild upset or even nausea.
- **The fight or flight response is a natural reaction of our body when we feel danger.** When we are in a dangerous situation, this is a very helpful. When our body reacts this way again and again because of mismanaged stress, there is a very high impact on our cardiovascular system. People who are irritable, angry and aggressive run a higher risk for heart disease. Stress can cause serious mental health and physical problems.

Activity 7: Brainstorming session on causes of stress

Learning Outcomes

- Identify symptoms of stress.
- Recognize signs of stress in yourself.

Instructions

Write this question on the flip chart: What can cause us stress?

Ask the participants to give their ideas. Write down the answers that are given and go over the list. Why are these things stressful?

Some of the answers you can expect include:

- Health problems/chronic illness
- Emotional problems
- Trouble with relationships/spouse
- Problems with children
- Job
- Illness in family
- Social situations
- Difficulty paying bills
- Going through a major life change
- Caring for an ill family member
- Second job
- Car problems
- Your environment
- Conflicts between what you value and how you act
- Addictions to drugs, alcohol, eating, shopping gambling or sex
- Keeping a secret

Write this question on the flip chart: What are the symptoms of stress?

Write down answers. Distribute handout, Warning Signs of Stress

Instructions:

Have the participants work in pairs to identify characteristics they see in themselves or others they work with or know. Allow ten minutes for small groups.

Ask what they learned or found significant in completing the handout.

Burnout

Key Points

- **When stress is not coped with effectively the result is burnout.** A person may feel overwhelmed, the work load too much with too many demands. The person is experiencing physical, emotional and mental exhaustion. Overwhelmed, the person's quality of life and work performance suffers.
- **Burnout happens when a person feels a loss of idealism and trust.** This can happen when a person has very high ideals and work does not have the same values.
- Some common feelings include:
 - Hopelessness – a feeling that things will never change
 - Negative attitude toward self, work, life and other people
 - Feelings of isolation
 - Lack of appreciation – little or no positive feedback
 - Feeling that there is not enough time to do a good job
 - Believing only your way is right
 - You must do every job yourself
 - Impatient or annoyed with others
 - Blaming others for not being as dedicated as you
- **People experience burnout in stages over time.**

Stage 1

A person may first feel irritable and anxious after work. It may be hard to transition from work to home life. Time and energy is spent worrying about the people they care for. A person is unwilling to take time off because no one can do things the way they do.

Stage 2

The feelings become more intense and a person may turn to alcohol or another substance and develop a substance abuse problem. As time goes on, resentment builds and the person may become withdrawn. Social relationships suffer when the person is unwilling to spend time with friends. Things may be put off because it is hard to make decisions.

Stage 3

A person may become exhausted, forgetful and unable to concentrate. Physical illness or depression may develop.

Conclusion

Turnover is a big issue for all settings in long term care. Workers lose their jobs. The person they cared for must get used to someone new who does not know them as well. It is a lose-lose situation. We can avoid burn out but it takes being honest with ourselves when the waning signs begin. Our jobs can be very rewarding and we are better able to provide care when we, as workers are happy and stress free. This may sound ideal, but it has many benefits. The person with dementia is aware of our stress level, and this can affect our ability to provide care that feels good to them, and to ourselves.

Activity 8: Stressful interactions in caring for a person with dementia

Learning outcomes

- Identify specific caregiving interactions that have been stressful in the past.
- Understand how you respond to those interactions.
- Identify other methods of dealing with stressful interactions.

Instructions

Write the title of the activity on the flip chart: Handling stressful situations with persons with dementia

Explain that you want them to think of a time when they had a stressful interaction with someone with dementia.

Write these questions on the flip chart:

- What happened?
- How did they respond to it?

Divide the group into pairs. Allow a five-ten minutes to write, and then ten minutes to share the information with another person. Then ask each person to share their experience. Use the flip chart to identify strategies people used in responding to the stressful situation.

Activity 9: Self-care

Learning objectives

- Identify factors that contribute to a worker not practicing self-care.
- State ways that a person can seek balance in their lives.

Key Point

- We have talked about the pitfalls of being a nurturing person. Some feel that it is impossible to take care of others and to take care of themselves.

Instructions

Write the word **Selfish** in the middle of the flip chart.

Ask the participants to define selfish. They may say that being selfish as caring solely or chiefly for one's self, or not considering others. After you have established a definition, write 'Self-care is.' above the word selfish on the flip chart so the entire saying is Self-care is Selfish.

Discussion questions

Do you feel that this is true of yourself or others you work with in long term care?

Why do nurturing people put their own needs last?

Allow time for the participants to express their feelings about self-care. Ask them to give examples of when they put their needs on hold to care for others. Encourage all to participate.

Instructions:

Give **Handout: Coping with stress**. Allow five to ten minutes for the workers to fill out

the form. Then ask the participants to turn to a partner and share what they learned.

Discussion questions

How do we know that we are out of balance, considering mind, body and spirit?

What are some of the things we do to relax or de-stress?

What are some strategies can we think of to replace our destructive coping methods with beneficial ones?

Conclusion

We sometimes let our needs go as we nurture others. Coping with stress in a healthy way and caring for ourselves is not selfish. Actually, it is a gift to others in that we can function in a healthy way. One way to be sure we make time is to write it into our weekly schedule. It is worth the investment.

How you cope with stress depends on:

- Cultural background
- Personality
- Past experience
- Family background
- Gender
- Lifestyle
- Personal spiritual beliefs
- Social support network
- Moral values

There are many benefits of stress management. A person can recognize and respond to early warning signs of stress. Becoming immediately aware of physical and emotional signs of stress can help us to cope better. Taking time for ourselves for quiet reflection or meditation can help us to feel more centered.

We gain a lot of strength from our jobs in helping others. The sense of purpose or self-direction can be very rewarding. We can support ourselves by taking time to be with our friends and family. A balance of

work and leisure keeps us going. Humor is very important in our lives.

Coping with grief and loss

Key Points

- **Burnout happens because of prolonged mismanagement of stress. One major stress for direct care workers is coping with grief and loss.** We are busy with our work from day to day and don't take time to grieve our losses. There are so many losses in long term care. It may be that a person becomes frail and unable to walk, they cannot remain in their homes or they die.
- **There is a lot of grieving going on in the process of dementia – by families, by the individuals with dementia, by staff.**
- **Losses experienced for families of persons with dementia.** The grieving process begins before the person dies and continues after death. Feelings of anger, guilt, sadness and fear are common. Families and spouses mourn the loss of the ability to communicate and the traditional roles of the family shift. Loss of feelings of security and control, denial, anger, shock, anguish, guilt and abandonment flare up for families. They may not believe that the person is ill. They may get frustrated with the person and then feel guilty. Many resent the demands of care giving and have feelings of failure. This may be true when the person has to move to a nursing home. Some family members feel guilty because they wish the person would die. They may regret things that happened in the past, or have unrealistic expectations of themselves. People can hold in their emotions and refuse to seek help.
- **The person with dementia also experiences losses.** Many of the above emotions are also experienced by the person as they learn about their

diagnosis. Over time, their inability to process information because of brain damage yields more losses. They no longer are trusted to keep the family checkbook, cannot bake like before or have the car keys taken away. When we are caring for someone over time, we watch as those losses happen, and we also grieve.

- **Sometimes we want to bury those emotions and just keep working, and not take time to grieve.**
- **As we are faced with loss and death in our jobs, it is helpful to stop and think about our own views.** What is your personal history related to death? What do you believe happens after a person dies? These answers may affect your ability to give good care. Personal growth comes from surviving loss.

Activity 10: Telling the story of someone special.

Learning outcomes

- Understand that it is healthy to experience grief and many different feelings in response to losses.
- Identify personal meaningful ways to respond to losses, including ceremonies, rituals. Staff may put up photos in a work area to remember someone who has died; it is very meaningful for staff to be included in writing to families after a death, including stories which will be treasured by families.

Instructions

Divide the participants into pairs. Write the questions on the flip chart and read them to the group. Give the pairs fifteen minutes to share their information. Have each person give a brief summary of their experience.

Discussion questions: Think of a favorite or difficult person that you cared for.

What was memorable about them?
What were your feelings after they died?
Did you have any feelings of guilt?
Was there something that was a little too close to home for you?
How did you get closure?

Discussion questions

Ask about the rituals or ceremonies people do to remember someone.

Why are these things meaningful?

Some ways we can cope with feelings of loss and grief:

- Keep a journal to help express your feelings.
- Share memories of the person with others in your agency who knew them.
- Talk to others about grief, guilt or anger.
- Find ways to forgive yourself, let go of unrealistic expectations.
- Find balance in your life through humor and scheduling fun activities.
- Nurture spiritual beliefs that support you, find time to meditate or sit quietly.
- Develop a special ritual or ceremony that helps you to mark the passing of someone special.

Conclusion

It is important to think about and be comfortable with your feelings. Many times, guilt is part of the process. Our memory of caring for someone keeps that person alive in our minds and hearts. Rituals and ceremonies help us to remember that person and find closure.

SLIPSHEET

Audi-Visual Resources

Recommended CDs / Videos / DVDs

Terra Nova Films, Inc. (largest source of videos/DVDs on age-related topics)
9848 South Winchester Ave., Chicago, IL
60643 800-779-8491

tnf@terranova.org

<http://www.terranova.org>

- Early Onset Memory Loss: A Conversation with Letty Tennis
- A Thousand Tomorrows: Intimacy, Sexuality, and Alzheimer's.
- Alzheimer's Disease: Inside Looking Out
- He's Doing This To Spite Me: Emotional Conflicts In Dementia Care
- Recognizing and Responding To Emotion In Persons With Dementia
- Bathing without a Battle
- Best Friends
- Bon Appetit! How To Create Meaningful Mealtimes In Long-Term Care
- Communicating With Moderately Confused Older Adults
- Communicating With Severely Confused Older Adults
- Complaints of a Dutiful Daughter
- Dress Him While He Walks: Behavior Management In Caring For Residents With Alzheimer's Disease
- Everyone Wins! Quality Care Without Restraints
- He's Doing This To Spite Me: Emotional Conflicts In Dementia Care
- More Than A Thousand Tomorrows
- Recognizing And Responding To Emotion In Persons With Dementia
- Time Slips

Duke University Media Services

Box 90846

Durham, NC 27708

919-681-2483

<http://www.geri.duke.edu/service/dfsp/about.htm>

- Alone But Not Forgotten: Serving People with Dementia Who Live Alone
- Caring About Howard
- Home is Where I Remember Things
- From Here to Hope

University of North Carolina and Oregon Health and Science University

<http://www.bathingwithoutabattle.unc.edu/ordering.htm>

- Bathing without a Battle

Video Press

School of Medicine University of Maryland

100 North Greene Street, Suite 300

Baltimore, Maryland 21201-1082

800-328-7450

videopressmail@som.umaryland.edu

http://www.videopress.org/Geriatrics_Alzh.html

- Grace

Fanlight Productions

www.fanlight.com

- Resisting Care...Putting Yourself in Their Shoes

The Leeza Gibbons Memory Foundation

3050 Biscayne Blvd. Suite 908

Miami, Florida 33137

888-655-3392

<http://www.memoryfoundation.org>

- The Family's Guide to Alzheimer's, volume 1-5
- Caregiver's Friend: Sensitive Conversations
- Caregiver's Friend: Dealing with Dementia

- Strategies for Dementia: Communications Skills for Professional Caregivers

CD: *The art of Meditation Four Classic Meditative Techniques Adapted for Modern Life*, Daniel Goleman, Ph.D.

Videos: *The Joy of Stress: How to Prevent Hardening of the Attitude and Humor your Stress: Jest for the fun of it*, both by Loretta LaRoche. Available at www.wgbh.org

Reference List

Alzheimer's Association (1997). *Key elements of dementia care*. Chicago: National Alzheimer's Association.

Alzheimer's Association (2007). *Alzheimer's Disease Facts and Figures*.

American Nurses Association. (1998). *Testimony of the American Nurses Association before the National Academy of Sciences Institute of Medicine Committee on Improving Quality in Long Term Care*. American Nurses Association Policy Series. Washington, DC.

American Psychiatric Association (1997). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. *American Journal of Psychiatry* 154: 1-39.

Andersen, C.K., Wittrup-Jensen, K.U., Lolk, A., Andersen, K. and Kragh-Sorensen, P. (2004). Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health and Quality of Life Outcomes*, 2:52.

Archibald, C., Carever, A., Keene, J. and Watson, R. (1994). *Food and nutrition in the care of people with dementia*. University of Stirling, Stirling FK9 4LA Scotland

Attix, D.K. and Welsh-Bohmer, K.A., Editors, (2006). *Geriatric neuropsychology: Assessment and intervention*. New York: Guilford Press, 2006.

Beck, C., Zgola, J. Shue, V. (2000). Activities of daily living: An essential component of programming for persons with Alzheimer's disease. *Alzheimer's Care Quarterly*, 1(2): 46-55.

Beck, C., Heacock, P., Mercer, S., Wall, R., Rapp, C, Vogelpohl, T. (1997) Improving dressing behavior in cognitively impaired nursing home residents. *Nursing Research* 46: 126-132.

- Beck, C., Vogelelphohl, T. (1995). Cognitive impairment and autonomy. In Gamroth, L. Semradek, M. and Tornquist, E., (eds). *Enhancing Autonomy in Long Term Care* pp. 44-57. New York: Springer.
- Bell, V. and Troxel, D. (1997). *The best friends approach to Alzheimer's care*. Baltimore: Health Professions Press, Inc.
- Bernstein, G (1999). "Human services?... That must be so rewarding." *A Practical Guide for Professional Development*, Second Edition. Baltimore: Paul H. Brooks Publishing Co.
- Bowlby, C. (1993). *Therapeutic activities with persons disabled by Alzheimer's disease and related dementias*. Gaithersburg, MD: Aspen Publishers.
- Bowlby Sifton, C. (2000). Well-being and doing: Enabling occupation with persons with dementia. *Alzheimer's Care Quarterly*, 1(2): 7-28.
- Brawley, E. (1997). *Designing for Alzheimer's disease: Strategies for creating better environments*. New York: John Wiley & Sons, Inc.
- Brody, E., Keblan, M., Lawton, M., and Silverman, H. (1971). Excess disabilities of mentally impaired aged: Impact of individualized treatment. *The Gerontologist* 11: 124-133.
- Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia*. London: Jessica Kingsley Publishers.
- Bump, L. (2004). *Life happens in the kitchen...how to make the kitchen the heart of your home*. Action Pact Workbook.
- Burns, A., Lawlor, B., and Craig, S. (1999). *Assessment scales in old age psychiatry*. London, England: Martin Dunitz.
- Chenoweth, L.L. (2001). Presentation, Eastern Michigan University.
- Chou, S.C. (2002). Staff satisfaction and its components in residential aged care. *International Journal for Quality in Health Care*, 14:3, 207.
- Cohen, D. (1991). The subjective experience of Alzheimer's disease: The anatomy of an illness as perceived by patients and families. *The American Journal of Alzheimer's Care and Related Disorders & Research*, May/June.
- Cohen-Mansfield, J. (2000). Theoretical Frameworks for Behavioral Problems in Dementia. *Alzheimer's Care Quarterly*, 1: 4, 8-21.
- Cohen-Mansfield, J. (2000) Approaches to the Management of Disruptive Behaviors. In P. Lauton and R. Rubinstein (eds.) *Interventions in Dementia Care: Toward Improving Quality of Life*. New York: Springer Publishing.
- Cohen-Mansfield, J., Marx, M.S. and Rosenthal, A.S. (1989). A description of agitation in a nursing home. *Journal of Gerontology*. 44, M77-M84.
- Corey, M. S. and Cory, G. (2007). *Becoming a helper*, Fifth Edition, Thomson Higher Education Belmont, CA.
- Cox, C.B., Ed., (2007). *Dementia and social work practice: Research and interventions*. New York: Springer Publishing.
- Davis, R. (1989). *My journey into Alzheimer's disease*. Wheaton, IL: Tyndale House Publishers, Inc.
- Fazio, S.; Seman, D.; and Stansell, J. (1999). *Rethinking Alzheimer's care*. Baltimore: Health Professions Press.
- Garthe, K. RN, MSN. Coach of Inpatient Services at Leelanau Memorial Health Center (LMHC). LMHC is organized around the concept of work teams for all areas. The Long Term Care unit emphasizes a social model of care. Phone 231-386-0027. Fax 231-386-0085. Email: kgarthe@mhc.net.

Gerontology Network Services, 4695 Danvers Drive, S.E., Grand Rapids, Michigan 49512. Some case studies adapted from GNS materials with permission.

Hall, G. and Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1, 399-406.

Harris, P.B., Ed. (2002). *The person with Alzheimer's disease: Pathways to understanding the experience*. Baltimore: The Johns Hopkins University Press.

Heacock, P., Walton, C., Beck, C., Mercer, S. (1991). Caring for the cognitively impaired: Reconceptualizing disability and rehabilitation. *Journal of Gerontological Nursing*, 17: 22-26.

Hellen, C. (1990). Eating: An Alzheimer's activity. *American Journal of Alzheimer's Care and Related Disorders and Research*, March/April, pp. 5-9.

Hellen, C. (1998). *Alzheimer's disease: Activity-focused care*. 2nd edition. Boston: Butterworth-Heinemann.

Henderson, C. S. and Andrews, N. (1998). *Partial view: An Alzheimer's journal*. Dallas: Southern Methodist University Press.

Hodgson, H. (1995). *Alzheimer's: Finding the words: A communication guide for those who care*. Minneapolis: Chronimed Publications

Jones, M. (1999). *GentleCare: Changing the experience of Alzheimer's disease in a positive way*. Vancouver: Hartley & Marks Publishers Inc.

Kane, R., Jordan, N., and Grant, L. (1998). Goals for Alzheimer's care in nursing homes: What kind of differences do special care units expect to make? *Journal of Health and Human Services Administration*, 20:311-332.

Kaplan, M. (1996). *Clinical practice with caregivers of dementia patients*. Washington D. C.: Taylor & Francis Publishers.

Kayser-Jones, J. and Schell, E. (1997). The mealtime experience of a cognitively impaired elder: Ineffective and effective strategies. *Journal of Gerontological Nursing*, 23(7), 33-39.

Killick, J. and Allan, K. (2001). *Communication and the care of people with dementia*. Buckingham: Open University Press.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia: Open University Press.

Kitwood, T. and Benson, S. (eds), (1995). *The new culture of dementia care*. London: Hawker Publications.

Kovach, C. (1997). *Late-stage dementia care: A basic guide*. Washington, DC: Taylor & Francis.

Kramer, N. and Smith, M. (2003) *Working together: nursing assistants help one another manage stress in the workplace*. Download it at www.sephardichome.org or contact Nanette A. Kramer at nk105@columbia.edu.

Kuhn, D. (2003). *Alzheimer's early stages: First steps in caring and treatment*, 2nd Edition. Alameda, CA: Hunter House Publishers.

Lane, P., Kuntupis, M., MacDonald, S., McCarthy, P.; et al. (2003 Jan) A pain assessment tool for people with advanced Alzheimer's and other progressive dementias. *Lane Home Healthcare Nurse*, 21(1), p. 32-7.

Logsdon, R., Gibbons, L., McCurry, S., and Teri L. (2002, May-June). Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*, 64(3), 510-19

- Macdonald, D. and Zgola, J. (1999). When is breakfast? Any time you want it. In J. Zgola, *Care that works: A relationship approach to persons with dementia*. Baltimore: The Johns Hopkins University Press.
- Maslow, K. and Whitehouse, P. (1997). Defining and measuring outcomes in Alzheimer disease research: Conference findings. Alzheimer's Disease Association.
- Ortigara, A. (2000). Understanding the language of behavior. *Alzheimer's Care Quarterly*, 1:4, pp. 89-92.
- Michigan Dementia Coalition (2006). *Knowledge and skills needed for dementia care: A guide for direct care workers*. Available in pdf file through State of Michigan website. http://www.michigan.gov/documents/miseniors/DemCompGuide_181812_7.pdf
- Mitelman, M.S., Epstein, C., and Pierzechala, A. (2003). *Counseling the Alzheimer's caregiver: A resource for health care professionals*. American Medical Association Press.
- Montgomery, R. (1983). "Staff-family relations and institutional care policies" *Journal of Gerontological Social Work*, v. 6(1).
- Moyle, W., Skinner, J., Rowe G. and Gork C. (2003) Views of job satisfaction and dissatisfaction in Australian long-term care. *Journal of Clinical Nursing* 12: 2, 168-176.
- Ortigara, A. (2000). Understanding the language of behavior. *Alzheimer's Care Quarterly*, 1:4, pp. 89-92.
- PHI (Paraprofessional Healthcare Institute), *Peer Mentoring Program*, available at www.directcareclearinghouse.org.
- Pillemer, Karl (1996). *Solving the frontline crisis in long-term care*. Cambridge, MA: Frontline Publishing Corporation.
- Rader, J. (1995). *Individualized dementia care: Creative, compassionate approaches*. New York, NY: Springer Publishing Co.
- Rader, J. & Barrick, A. (2000). Ways that work: Bathing without a battle. *Alzheimer's Care Quarterly*, 1:4, pp. 35-49.
- Reisberg, B. (1983). *Alzheimer's disease: The standard reference*. New York: Free Press.
- Riggs, C. J., and Rantz, M. J. (2001). A model of staff support to improve retention in long-term care. *Nursing Administration Quarterly*, 25:2 (Winter 2001), 43.
- Robinson, A., Spencer, B. & White, L. (1998). *Understanding difficult behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses*. Ypsilanti, MI: Eastern Michigan University
- Robinson, E. and B. Leif (1998). *Nutrition management and restorative dining for older adults: Practical interventions for caregivers*. Available from the American Dietetic Association.
- Rogers, J., Holm, M, Burgio, L. et al. (1999). Improving morning care routines of nursing home residents with dementia. *Journal of the American Geriatrics Society* 47: 1049-1057.
- Sabat, S.R. (1998). Voices of Alzheimer's disease sufferers: A call for treatment based on personhood. *Journal of Clinical Ethics*, 9: 35-48.
- Sabat, S.R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell Publishers.
- Schacter, D.L. (1996). *Searching for memory: The brain, the mind, and the past*. Basic Books.
- Schulz, R., Ed. (2000). *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*. New York: Springer Publishing Company.

Sheard, D, Editor (2003). *Make a difference in dementia care training*. Alzheimer's Society, United Kingdom.

Sheard, D. (2000). *Dementia care planning: A guide for branches*. Alzheimer's Society, U.K.

Simard, J. (1999). The lifestyle approach. In Volicer, L. and Bloom-Charette, L. (eds). *Enhancing the quality of life in advanced dementia*, (pp.38-55). Philadelphia: Brunner/Mazel.

Snyder, L. (1999). *Speaking our minds: Personal reflections from individuals with Alzheimer's*. New York: W.H. Freeman and Company.

Stern, L. and Fogler, J. (2005). *Improving your memory: How to remember what you are starting to forget*, 3rd Edition. Johns Hopkins Press.

Stokes, Graham. (2000). *Challenging behaviour in dementia. A person-centered approach*. United Kingdom: Speechmark Publishing, Ltd.

Talerico, K. and Evans, L. (2000). Making sense of aggressive/protective behaviors in persons with dementia. *Alzheimer's Care Quarterly*, 1:4, pp. 77-88.

Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore: Health Professions Press.

Teri, L. & Lodgson, R.G. (1991) Identifying pleasant activities for Alzheimer's disease patients: The Pleasant Events Schedule – AD. *The Gerontologist*, 31, pp. 124-27.

Wagland, J. and G. Peachment. *Chairs: Guidelines for the purchase of lounge, dining and occasional chairs for elderly long term residents*. University Of Stirling, Stirling FK9 4LA, Scotland.

Weaverdyck, S. (1991). Assessment as a basis for intervention. In *Specialized Dementia Care Units*, edited by D. Coons.

Baltimore, MD: John Hopkins University Press.

Weaverdyck, S. (1990). Neuropsychological assessment as a basis for intervention in dementia. In N.Mace, (Ed.) *Dementia care: Patient, family and community*. Baltimore, MD: Johns Hopkins University Press.

Weaverdyck, S. *Caring Sheets*. Available online at <http://www.lcc.edu/mhap/>.

Weaverdyck, S., Wittle, A., and deLaski-Smith, D. (1998). In place progression: Lessons learned from the Huron Woods staff. *Journal of Gerontological Nursing*, January, 24 (1): 31-39.

White, L. and Spencer, B. (2006). *Moving a relative with memory loss: A family caregiver's guide*, 2nd Edition. Whisp Publications. www.whisppub.com

Womach, P. (1996). *Scoop it. Mold it. Pipe it! Dysphagia texture with thickeners*. WA: Challenge Book Publishing.

Yesavage, J.A., Brink. T.L., Lum, O., Huang, V., Adey, M., and Leirer, O. (1983) Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research* 17, pp. 37-49.

Zgola, J. (1999). *Care that works: A relationships approach to persons with dementia*. Baltimore: The Johns Hopkins University Press.

Zgola, J. and Bordillon, G. (2001). *Bon appetit!* Baltimore: Health Professions Press. Book and 2 videocassettes available.

Books recommended for family caregivers: American Medical Association, (2001). *AMA guide to home caregiving*. AMA: John Wiley & Sons.

Bell, V. and Troxel, D. (2005). *A dignified life: The best friends approach to Alzheimer's care, A guide for family caregivers*. Baltimore: Health Professions Press.

Bowlby Sifton, C. (2004). *Navigating the Alzheimer's journey: A compass for caregiving*. Baltimore: Health Professions Press.

Kuhn, D. (2003). *Alzheimer's early stages: First steps in caring and treatment*, 2nd Edition. Alameda, CA: Hunter House Publishers.

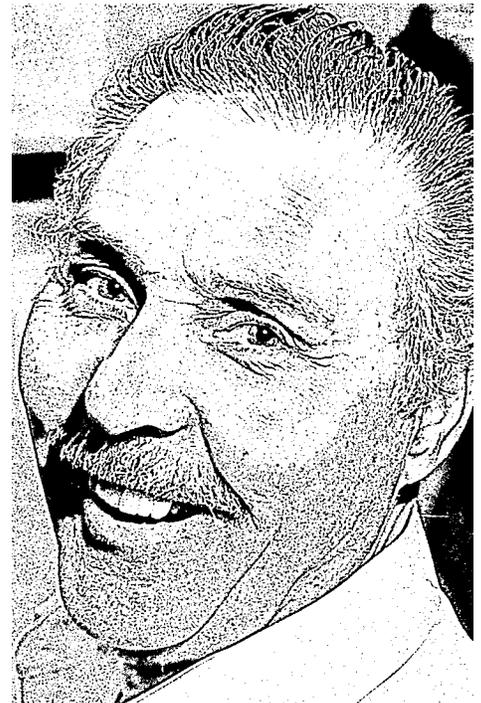
Meyer, M.M. and Derr, P. (2007). *The comfort of home: A complete guide for caregivers*, 3rd Edition. Care Trust Publications, 800/565-1533.

Radin, L. and Radin, G., Eds. (2003). *What if it's not Alzheimer's? A Caregiver's guide to dementia*. New York: Prometheus Books.

Robinson, A., Spencer, B. & White, L. (1998). *Understanding difficult behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses*. Ypsilanti, MI: Eastern Michigan University

Shanks, L.K. (1999) *Your name is Hughes Hannibal Shanks: A caregiver's guide to Alzheimer's*. Penguin Books.

White, L. and Spencer, B. (2006). *Moving a relative with memory loss: A family caregiver's guide*, 2nd Edition. Whisp Publications. www.whisppub.com





Knowledge and Skills Needed for Dementia Care

A Guide for Direct Care Workers

• • •



2006

Mission

To identify the standards to guide direct care workers in their efforts to provide excellent dementia care.

Vision

All direct care workers will have knowledge, skills and empathy to work with individuals with dementia and their families to provide high quality dementia care.

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How to Use This Guide

Providing excellent care assistance for someone with dementia requires special knowledge and skills. In our experience, the rewards of sharing life with someone with dementia increase as our knowledge increases. Some of us have been learning about dementia care for many years. We have discovered that our growing knowledge gives us new ideas and insight, increasing the satisfaction we feel in interacting with someone with dementia. We learn from our own experiences, from the experiences of others, and from research findings. We are never finished learning. We can always learn more.

This guide is meant to help direct care workers¹ identify the knowledge and skills needed for providing ideal dementia care. Our vision for direct care workers is that we will be knowledgeable, skillful, and empathic in working with individuals with dementia and their families.

The knowledge and skills identified in this guide are only part of a broader set of competencies that direct care workers need. The guide identifies the special care assistance skills that are important when working with a person with dementia. It assumes that readers already have the broader set of knowledge and skills. For example, the guide assumes that the reader knows that hydration is a concern for all persons receiving care. When the person has dementia, however, hydration becomes an even greater concern since a person with dementia is more likely to forget to drink fluids. The guide identifies hydration as a special concern for individuals with dementia. Likewise, self-care is clearly an important skill area for all direct care workers, including those who do not work with persons with dementia. It is included in this guide as an area of dementia competency because some direct care workers find dementia care unusually demanding at the same time that it is especially rewarding.

You may notice that some knowledge items or skills appear in more than one place in the guide. We have tried to avoid too much redundancy but have sometimes included an item in more than one place because of its relevance to more than one topic.

One way to use this guide is to look through the competency areas and think about in which areas you have more knowledge and in which ones you have less. If you come across terms or phrases that are not familiar to you, learn about these terms and concepts by reading or viewing the Suggested Resources for that competency area. The Suggested Resources lists books, articles, videos, and DVDs that can help you learn more.

Another way to use the guide is to browse through it and find topics that intrigue you. Again, the Suggested Resources will point you to resources. Or you may wish to find a workshop or class that addresses a specific skill or knowledge area. You can find a Dementia Education and Training Directory for Michigan at www.dementiacoalition.org.

Competency is the ability to perform well. Knowledge provides a basis for competency, but may not be enough by itself. A desire to improve and *practice* help build competency. Competencies may also be thought of as standards or measures of behavior. The competencies for good dementia care are the standards or measures of care giving behavior that best support the person in one's care.

¹ Direct-care workers include certified nursing assistants (CNAs), home health aides, personal care assistants, direct support professionals, and volunteers providing supportive services in individual, acute care, and long-term care settings.

The Suggested Resources section provides resource suggestions for each competency area or topic. The References section lists all resources alphabetically. It includes all of the items listed in Suggested Resources plus additional items.

In our ongoing quest for more knowledge and better understanding, we hope to produce a new and improved guide in the future. You can help us by providing your comments on this guide. What have been your experiences as a direct care worker with persons with dementia? What have you learned that you would like to share with others? We are also interested in your response to this guide. What is most helpful? What is least helpful? What can be done to make it better? Please send us your feedback. A form is provided in Appendix C, or you are welcome to email or mail your thoughts.



Competency Areas and Objectives

A. Knowledge of Dementia Disorders

1. Identify the primary causes of dementia.
2. Differentiate between irreversible and reversible dementia.
3. Understand the definition and significance of delirium.
4. Describe how brain changes affect the way a person functions and behaves.
5. Discuss why it is important to individualize the care you provide to someone with dementia.

B. Person-Centered Care

1. Discuss the key concepts of person-centered care.
2. Describe how the background, culture, and experiences of a person with dementia affect care.
3. Describe how *your* background, culture, experiences, and attitudes affect care.

C. Care Interactions

1. Provide appropriate assistance with basic physical care tasks.
2. Identify and address the unique safety needs of persons with dementia.
3. Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.
4. Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.
5. Identify and validate the feelings, expressed verbally or nonverbally, of the person.
6. Demonstrate effective ways of listening to and communicating with someone who has dementia.
7. Discuss how various aspects of the environment may affect a person with dementia.
8. Understand why a person with dementia may be more vulnerable to abuse and neglect.

D. Enriching the Person's Life

1. Support and encourage individuals to maintain their customary activities, social connections, and community involvement.
2. Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.
3. Recognize the role of pleasurable activities, including sexuality and intimacy, in a person's life.

E. Understanding Behaviors

1. Understand that behavior is usually a form of communication and often represents an unmet need.
2. Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space).
3. Describe effective responses to behaviors that may be perceived as "challenging."

F. Interacting with Families

1. Respond to the family's unique relationships, experiences, cultural identity, and losses.
2. Use a non-judgmental approach with family members or when talking about the family with other staff.
3. Recognize the family as part of the caregiving team.

G. Direct Care Worker Self-Care

1. Identify personal feelings, beliefs, or attitudes that may affect your caring relationships.
2. Identify helpful ways to prevent and cope with stress and burnout.
3. Identify the ways you cope with grief and loss.
4. Explain effective ways to talk with employers and co-workers about differences in philosophy or implementation of care practices, with a focus on what is best for the person with dementia.

Philosophy and Values

Life is a journey that revolves around relationships. The development of quality life-enhancing relationships gives meaning and purpose to the interactions between individuals with dementia, families, and Direct Care Workers (DCWs). These competencies are based on a philosophy that values age- and culturally-appropriate, person-centered care. This approach supports continued learning, growth, and development of compassionate relationships in a nourishing environment. The competencies emphasize that DCWs are an integral part of the caregiving team, whose contributions are valued and respected. The competencies focus on assisting DCWs in developing holistic, interpersonal, problem solving, and communication skills with persons, families, and staff in an environment that is supportive, vibrant, and meaningful.

Person-Centered Care

Care that is person-centered is care that focuses on each individual with respect to her or his unique history, abilities, experiences, culture, and personality. People with dementia retain the ability and the right to communicate their likes, dislikes, and preferences. Quality care relies on collaboration between the individual, the person's family, and the DCW.

Growth- and Caring-Centered

Care that is growth- and caring-centered is defined as helping another person to grow and develop. Part of the caring process is acknowledging an individual's needs,² including the opportunity to give care as well as receive it. This caring process may continue through the last stages of life.

Supportive Environment

The physical and social environment plays an integral role in all care settings. The environment should foster socialization, independence, and meaningful activity and offer a sense of community, safety, comfort, privacy, and dignity for everyone. Relationship building is fostered in an environment where interactions take place naturally.

Direct Care Workers

DCWs reach their full potential when the relationships they form are meaningful, standards of excellence are in place, opportunities are available to grow personally and professionally, and their accomplishments are not only acknowledged, but also celebrated. A learner-centered approach to training empowers DCWs to be creative and forward thinking; it allows them to take ownership of their work and to break the mold by testing innovative ideas. Often the best care is provided when decision-making begins with persons with dementia or with those closest to them, which is often the DCW.

See Contribution to the Philosophy and Values Statement in Appendix A.

²Including the need for companionship, autonomy, dignity, individuality, meaningful activity, productivity, physical comfort, emotional security, and spiritual well-being.

A. Knowledge of Dementia Disorders

As a DCW who is knowledgeable about dementia disorders, you are able to:

1. Identify the primary causes of dementia.
2. Recognize the difference between irreversible and reversible dementia.
3. Understand the definition and significance of delirium.
4. Describe how brain changes affect the way a person functions and behaves.
5. Explain why it is important to individualize the care you provide to someone with dementia.

• • •

1. Identify the primary causes of dementia.

- 1.1 Explain that there are many causes of dementia and that dementia itself is not a disease, but a group of symptoms that vary.
- 1.2 Recognize the key characteristics (such as progression and behaviors) of diseases and disorders that cause dementia, such as:
 - Alzheimer's disease
 - Lewy body disease
 - Vascular disease
 - Frontotemporal disorders
 - Parkinson's disease
 - Head trauma
 - Huntington's disease
 - Substance-induced disorders
 - HIV-AIDS

Dementia is a group of symptoms (not a disease). It is a decline in the ability to think that persists long enough and is severe enough to interfere with routine daily activities. Dementia usually begins gradually and persists indefinitely.

Delirium describes a state of confusion that usually begins suddenly and ends fairly quickly. It may include agitation, anxiety, illusions, hallucinations, distractibility, hyperactivity, disorientation, disordered speech, and defective perception.

2. Recognize the difference between irreversible and reversible dementia.

- 2.1 Recognize the potential symptoms and causes of reversible dementia.
- 2.2 Understand that there are reversible types of dementia, in which the symptoms can be alleviated with proper treatment.

- 2.3 Understand that treatment may delay decline and improve quality of life for a person with an irreversible dementia.
 - 2.4 Explain why it is crucial for a person with dementia to receive an accurate diagnosis.
- 3. Understand the definition and significance of delirium.**
- 3.1 Understand that delirium is an acute medical condition that can be fatal if not treated.
 - 3.2 Recognize the symptoms and causes of delirium.
- 4. Describe how brain changes affect the way a person functions and behaves.**
- 4.1 Describe the typical progression of dementia symptoms.
 - 4.2 Recognize that different types of dementia affect different parts of the brain.
 - 4.3 Recognize that different types of dementia have different stages.
 - 4.4 Recognize that different types of dementia have different effects on behaviors.
 - 4.5 Recognize that an individual may have more than one dementia-related diagnosis.
 - 4.6 Recognize that an individual may have more than one area of brain changes.
 - 4.7 Recognize the symptoms that suggest the onset of active dying.
- 5. Discuss why it is important to individualize the care you provide to someone with dementia.**
- 5.1 Understand that each person's symptoms and progression are unique.
 - 5.2 Understand that each person's symptoms and progress may vary significantly from what is typical.
 - 5.3 Recognize how care may be different depending on the type of dementia the person has.

B. Person-Centered Care

As a DCW who is person-centered, you can:

1. Discuss the key concepts of person-centered care.
2. Describe how the background, culture, and experiences of a person with dementia affect care.
3. Describe how *your* background, culture, experiences, and attitudes affect care.

• • •

1. Discuss the key concepts of person-centered care.
 - 1.1 Identify ways to see the person with dementia as a unique individual.
 - 1.2 Explain the importance of relating to the person with dementia as a whole person (physical, emotional, and cognitive; past, present and future).
 - 1.3 Explain the importance of focusing on the person's feelings more than on the task.
 - 1.4 Recognize the person's ability to make decisions and express choices until the end of life.
 - 1.5 Identify ways to enhance the person's ability to make decisions.
 - 1.6 Identify how to offer choices in ways that are appropriate to the individual's ability to choose.
 - 1.7 Identify ways to keep the decision making power in the hands of the individual or those closest to her or him.
 - 1.8 Acknowledge that people with dementia are entitled to opportunities and risks in life.
 - 1.9 Explain the difference between *doing for* the person and *partnering with* the person.

Person-centered care is a widely used term with many meanings. Here we use the term to refer to care that takes into account that each person is unique. Person-centered care respects and honors individual differences. Each person with dementia has his or her own history, personality, needs, and wishes. Person-centered care offers the person with dementia choices within her ability to choose. Providing person-centered care means *taking the time* and *making the effort* needed to know the person as an individual so that her unique individuality is honored.

2. Describe how the background, culture, and experiences of a person with dementia affect care.

- 2.1 Describe how the person with dementia may experience the surrounding world.
- 2.2 Recognize the importance of establishing familiar routines to promote individualized care.
- 2.3 Identify ways to establish familiar routines to promote individualized care.
- 2.4 Describe the importance of being flexible in meeting individual needs.
- 2.5 Discuss things you can do to identify the person's remaining skills and abilities.
- 2.6 Describe ways you can encourage the person to use remaining skills and abilities.
- 2.7 Recognize that every individual has a need for:

- Attachment to others
- Inclusion
- Occupation
- Individuality
- Dignity
- Emotional security
- Privacy
- Intimacy and touch
- Socialization
- Meaning
- Physical comfort
- Meaningful activities

2.8 Recognize and encourage each person's ability to:

- Grow
- Connect
- Give
- Receive
- Teach

2.9 Identify ways to help the person fulfill the need to be a member of a community.

3. Describe how *your* background, culture, experiences, and attitudes affect care.

- 3.1 Acknowledge the importance of working as a team with individuals with dementia, families, and other staff.
- 3.2 Describe the importance of understanding each person's unique story without judgment or prejudice.
- 3.3 Recognize how your own experience and background affect caregiving.

C. Care Interactions

As a dementia-competent DCW, you are able to:

1. Provide appropriate assistance with basic physical care tasks.
2. Identify and address the unique safety needs of persons with dementia.
3. Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.
4. Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.
5. Identify and validate the feelings, expressed verbally or nonverbally, of the person.
6. Demonstrate effective ways of listening to and communicating with someone who has dementia.
7. Discuss how various aspects of the environment may affect a person with dementia.
8. Understand why a person with dementia may be more vulnerable to abuse and neglect.

• • •

1. Provide appropriate assistance with basic physical care tasks.
 - 1.1 Understand that appropriate assistance is most likely different for each individual, and may even vary for the same individual depending on the present circumstances.
 - 1.2 Provide assistance with eating in the manner appropriate for the person.
 - 1.3 Promote adequate hydration.
 - 1.3.1 Recognize that individuals with dementia may not feel thirsty.
 - 1.3.2 Recognize that individuals with dementia may not voice or act on feelings of thirst.
 - 1.4 Use techniques that facilitate the person's necessary hygiene while minimizing distress.
 - 1.5 Recognize and respond appropriately to signs or symptoms of pain or discomfort.
 - 1.6 Prevent or minimize pain and discomfort when assisting the individual with physical movement.

2. **Identify and address the unique safety needs of persons with dementia.**
 - 2.1 Identify ways to reduce risks and prevent injury.
 - 2.2 Recognize that as dementia progresses, the person's abilities change.
 - 2.3 Use problem solving and creativity to adapt the person's environment to ensure safety.
 - 2.4 Recognize changes that can affect safety, such as changes in judgment, sense of time and place, behavior, physical ability, and senses.
 - 2.5 Understand the risks of wandering and minimize threats.
 - 2.6 Understand the risks of weapons and address appropriately (according to agency policies or as needed to ensure safety).
 - 2.7 Recognize the increased need for assistance in emergencies of the person with dementia.
 - 2.8 Describe basic emergency assistance steps.

3. **Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.**
 - 3.1 Recognize that independence is a goal as long as it enhances the person's self-esteem, pleasure, and confidence.
 - 3.2 Understand that some challenges may be stimulating and maximize independence, yet can also overwhelm and tire the person.
 - 3.3 Recognize the person's ability to participate in activities.
 - 3.4 Simplify activities, break down tasks, or provide assistance to help the individual achieve the highest possible level of independent functioning.
 - 3.5 Recognize that the person's abilities fluctuate.
 - 3.6 Recognize that different dementias affect abilities and functioning in different ways.
 - 3.7 Offer choices as appropriate when providing care.
 - 3.8 Discuss how using prompts can help the person function.
 - 3.9 Recognize the signs or characteristics that suggest palliative or hospice care may be appropriate and discuss with your supervisor.

4. **Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.**
 - 4.1 Recognize that gathering information about the person is an ongoing process.
 - 4.2 Recognize that you play a key role in the process of gathering information and sharing it with family members and other staff.

Palliative care is sometimes called "comfort care." It is care that focuses on making sure that a person is comfortable rather than on trying to cure. Palliative care seeks to ensure that remaining life is of the highest quality possible, but does not try to prolong life.

- 5. Identify and validate the feelings, expressed verbally or nonverbally, of the person.**
- 5.1 Understand that the person with dementia responds to your emotional state and the emotional state of others within the environment.
 - 5.2 Respond appropriately to the feelings expressed by the person.
 - 5.3 Describe a variety of behaviors a person with dementia may use to express feelings.
- 6. Demonstrate effective ways of listening to and communicating with someone who has dementia.**
- 6.1 Recognize the person's ability to communicate verbally and nonverbally.
 - 6.2 Make sure you have the person's attention before making a request or introducing a task.
 - 6.3 Demonstrate effective listening skills.
 - 6.4 Demonstrate ways to adapt your communication to changing abilities of the person with dementia.
 - 6.5 Communicate in ways that provide physical and emotional comfort to those experiencing loss or actively dying.
- 7. Discuss how various aspects of the environment may affect a person with dementia.**
- 7.1 Recognize that the environment includes social, physical, and organizational components.
 - 7.2 Recognize that the individual's environment can promote or inhibit:
 - Autonomy
 - Personalization
 - Sense of well-being
 - Orientation and way-finding
 - Privacy
 - Safety
 - Social interaction
 - Physical comfort
 - 7.3 Discuss how to identify environmental "triggers" that may create stress for the person.
 - 7.4 Describe how to change the environment to support or improve the person's quality of life.
 - 7.5 Discuss the importance of ongoing changes in the environment to meet the person's needs.

8. Understand why a person with dementia may be more vulnerable to abuse and neglect.

- 8.1 Recognize that caring for a person with dementia may evoke feelings and thoughts that undermine your ability to provide compassionate care.
- 8.2 Recognize signs of physical, psychological, sexual, and financial abuse.
- 8.3 Recognize signs of physical or psychological neglect.
- 8.4 Recognize when and how to seek help or clarification.



D. Enriching the Person's Life

As a dementia-competent DCW, you can:

1. **Support and encourage individuals to maintain their customary activities, social connections and community involvement.**
2. **Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.**
3. **Recognize the role of pleasurable activities, including sexuality and intimacy, in the person's life.**

• • •

1. **Support and encourage individuals to maintain their customary social connections and community involvement.**
 - 1.1 Assist the person in engaging in individualized, meaningful activities that foster positive interaction, self-esteem, and personal identity.
 - 1.2 Recognize the importance of supporting the person's inclusion as a productive member in a community.
 - 1.3 Recognize that individuals may need their customary social connections and community involvement for spiritual fulfillment.
2. **Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.**
 - 2.1 Understand that activities can be simple and adjusted to the person's ability without being childish.
 - 2.2 Encourage individuals to do as much as they can for themselves in order to maintain their dignity and highest level of functioning.
 - 2.3 Understand that activities should be tailored to each person in light of the individual's history, experience, cultural background, and identity.
 - 2.4 Understand that abilities are fluid and recognize the importance of adapting activities and tasks as the disease progresses.
 - 2.5 Understand the importance of physical activity in maintaining the person's independence and abilities.
 - 2.6 Identify reasonable expectations of the person's ability in light of the disease process.
 - 2.7 Understand the importance of the moments of joy.
 - 2.8 Understand the importance of individuals reviewing their lives in order to identify remaining goals, tie up any loose ends, make peace, and leave a legacy.

- 2.9 Recognize that the person with dementia can continue to benefit from new experiences.
 - 2.10 Recognize that all activities can be adapted to the person's ability.
 - 2.11 Understand the importance of respecting the customary routines and daily pleasures of the person.
3. **Recognize the role of pleasurable activities, including sexuality and intimacy, in the person's life.**
- 3.1 Understand the person's need for intimacy and sexuality.
 - 3.2 Allow expression of sexuality that does not harm or threaten others.
 - 3.3 Discuss how the various forms of dementia may affect the expression of sexuality.
 - 3.4 Recognize the difference between sexuality and intimacy.
 - 3.5 Understand that people never lose the need for touch.
 - 3.6 Be mindful to protect the dignity of every individual.
 - 3.7 Be creative and generous with non-sexual forms of appropriate touch, such as massage, manicures, pedicures, hair combing, etc.
 - 3.8 Experiment with all the senses to create pleasure. Examples include music and aromatherapy.
 - 3.9 Recognize without judgment the need of the person to be attractive and desirable.
 - 3.10 Recognize that individuals with dementia can still enjoy humor.
 - 3.11 Understand that everyone has a different idea of what is funny and appropriate.
 - 3.12 Ensure that individuals with dementia never feel that you are laughing at them.

E. Understanding Behaviors

As a DCW who understands the behaviors of persons with dementia, you can:

1. **Understand that behavior is usually a form of communication and often represents an unmet need.**
2. **Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space.)**
3. **Describe effective responses to behaviors that may be perceived as "challenging."**

• • •

1. **Understand that behavior is usually a form of communication and often represents an unmet need.**
 - 1.1 Discuss common need-driven behaviors in dementia, such as verbal or physical agitation or aggression.
 - 1.2 Use non-judging, strengths-oriented language when describing behavior.
 - 1.3 Demonstrate awareness that the words and behavior of a person with cognitive impairment, even though seemingly aimed at you, should not be taken personally.
 - 1.4 Respond appropriately to signs of depression.
 - 1.8.1 Understand the increased risk of depression.
 - 1.8.2 Understand the increased risk of depression not being recognized.
 - 1.8.3 Understand the increased risk of depression not being treated.
 - 1.8.4 Explain the benefits of treating depression in a person with dementia.
 - 1.8.5 Recognize the signs of depression in a person with dementia.
2. **Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space.)**

- 3. Describe effective responses to behaviors that may be perceived as “challenging.”**
- 3.1 Recognize that our personal perceptions often determine whether a particular behavior is seen as challenging.
 - 3.2 Discuss how to identify the need that underlies the behavior.
 - 3.2.1 Recognize the importance of attending to and understanding the context within which a behavior occurs, including what happens before and after the behavior.
 - 3.3 Discuss how to identify the need that underlies the behavior.
 - 3.3.1 Identify underlying needs that may lead to certain behaviors:
 - Physical comfort
 - Emotional well-being
 - Sense of competency
 - Need for socialization
 - Ability to find one’s way
 - Desire to be understood
 - Desire to communicate effectively
 - 3.3.2 Understand how to engage in basic problem solving in order to identify potential causes.
 - 3.3.3 Understand the importance of tracking and reporting behavioral and mental status changes.
 - 3.3.4 Demonstrate how to track and report behavioral and mental status changes.
 - 3.4 Respond appropriately to verbal and nonverbal indicators of unmet needs.
 - 3.5 Prevent or decrease the incidents of “challenging” behaviors by identifying and meeting the needs of the person.
 - 3.6 Adjust your care approach, communication, and attitude to constructively respond.
 - 3.6.1 Use validation and redirection.
 - 3.6.2 Offer simple choices.
 - 3.6.3 Alter the environment.
 - 3.6.4 Alter the task or activity.
 - 3.7 Demonstrate the ability to be flexible, creative, and able to try several different approaches to address potential causes.
 - 3.9 Identify when, how, and what information to seek from family and other caregivers.
 - 3.10 Identify how to evaluate the individual’s response to an intervention and its effectiveness.
 - 3.11 Identify the possible effects of chemical (medication) and physical restraint.
 - 3.12 Explain the importance of using the least restrictive restraint when necessary.

F. Interacting with Families

As a DCW competent to interact with the families of persons with dementia, you can:

1. Respond to the family's unique relationships, experiences, cultural identity, and losses.
2. Use a non-judgmental approach with family members or when talking about the family with other staff.
3. Recognize the family as part of the caregiving team.

• • •

1. Respond to the family's unique relationships, experiences, cultural identity, and losses.
 - 1.1 Use effective listening skills to learn from the family about the person's individual history, preferences, etc.
 - 1.2 Recognize that the family's ethnicity and culture affect how family members understand dementia.
 - 1.3 Recognize that the family's ethnicity and culture affect how family members define their roles and responsibilities.
 - 1.4 Recognize the other roles and responsibilities family members may have, such as caring for both children and parents that affect their role as caregivers for the person with dementia.
 - 1.5 Recognize that feelings of guilt, grief, uncertainty, and stress may affect how family members communicate with each other and others.
 - 1.6 Demonstrate a basic knowledge of family dynamics and their effect on caregiving.
 - 1.7 Recognize that you may never know what a family member has experienced with the individual, and avoid judgment and criticism.
 - 1.8 Recognize that a person with dementia may be vulnerable to abuse or neglect by family members.
 - 1.9 Recognize that individuals living with persons with dementia may be vulnerable to being abused or neglected.
 - 1.10 Respond appropriately to signs of depression in family caregivers.
 - 1.10.1 Understand the increased risk of depression for family caregivers.
 - 1.10.2 Explain the benefits of treating depression in family caregivers.
 - 1.10.3 Recognize the signs of depression in family caregivers.

2. **Use a non-judgmental approach with family members or when talking about the family with other staff.**
 - 2.1 Understand that all families are different.
 - 2.2 Recognize the effect of your own family values on caregiving relationships.
 - 2.3 Recognize that families may express negative emotions and understand how to respond without taking it personally.
 - 2.4 Demonstrate understanding of how your own ethnic and cultural values influence your interactions.

3. **Recognize the family as part of the caregiving team.**
 - 3.1 Recognize each family member's level of understanding and acceptance of the disease process.
 - 3.2 Provide information and support as appropriate.
 - 3.3 Assist family members in learning more about dementia as appropriate.
 - 3.4 Model new skills and approaches for family members as appropriate.
 - 3.5 Encourage family members to use new skills and approaches as appropriate.
 - 3.6 Discuss the role of families in decision-making.
 - 3.7 Identify issues that may affect the relationship between staff and family members.
 - 3.8 Work with the family to create consistency for the person with dementia. Examples include a consistent schedule, consistent activities, and consistent responses to a particular behavior.
 - 3.9 Communicate effectively with the family regarding caregiving issues, such as changes in functioning or mood.

G. Direct Care Worker Self-Care

As a DCW who cares for yourself, you will:

1. **Identify personal feelings, beliefs, or attitudes that may affect your caring relationships.**
2. **Identify helpful ways to prevent and cope with stress and burnout.**
3. **Identify the ways you cope with grief and loss.**
4. **Explain effective ways to talk with employers and co-workers about differences in philosophy or care practices, with a focus on what is best for the person with dementia.**

• • •

1. **Identify personal feelings, beliefs, or attitudes that may affect your caring relationships.**

- 1.1 Recognize when you feel uncomfortable with certain characteristics or differences in other people.
- 1.2 Discuss your ethical responsibility, as a care provider, to respect others and be open to learning about differences.
- 1.3 Understand how your own experience and history influence your perception of others.³
- 1.4 Explain how your perception of others may affect how you provide care.
- 1.5 Identify characteristics such as race, culture, ethnicity, sexual orientation, religious beliefs, lifestyle, and weight that make you feel uncomfortable or negative.
- 1.6 Describe ways you cope with situations in which you have strong personal responses.
- 1.7 Recognize when and how to seek help with your feelings.

2. **Identify helpful ways to prevent and cope with stress and burnout.**

- 2.1 Recognize typical signs of stress, burnout, or depression.
- 2.2 Understand how you respond in stressful situations.
- 2.3 Identify specific caregiving interactions that have been stressful in the past.
- 2.4 Discuss your personal signs of stress or burnout.
- 2.5 Explain the benefits of addressing stress, burnout, or depression.
- 2.6 Identify methods of self-care and the coping strategies that work well for you.
- 2.7 Respond appropriately when you experience stress, burnout, or depression.

³Include in your review any experiences with: Physical abuse, psychological abuse or neglect, sexual abuse, and disrespectful treatment of your property, environment, or self.

2.8 Recognize when and how to seek assistance.

3. Identify the ways you cope with grief and loss.

3.1 Recognize that over time individuals with dementia and those close to them experience many kinds of physical, emotional, and social losses.

3.2 Understand that it is healthy to experience grief and many other feelings in response to losses.

3.3 Identify personally meaningful ways, such as rituals, ceremonies, special clothing, etc., to respond to losses.

4. Explain effective ways to talk with employers and co-workers about differences in philosophy or care practices, with a focus on what is best for the person with dementia.

3.1 Recognize that your knowledge, experience, and insight can make a valuable contribution to the care team's understanding.

3.2 Recognize that others' knowledge, experience, and insight can make a valuable contribution to the care team's understanding.

Suggested Resources

To assist you in your dementia studies and professional development, some of the resources that work group members have identified as favorites are listed below by competency area. These are only a small number of the many good resources available. The inclusion of any particular resource is not intended as an endorsement. *Find additional resources in the References section that follows this section.*

We suggest you first check with your local library for any resource you would like to borrow. You may be able to place a special order from a local bookstore or purchase an item via the Internet. If you would like assistance in locating or obtaining a resource, contact the Mental Health & Aging Project or the Alzheimer's Association:

Mental Health & Aging Project

Tel: (517) 483-1529

Fax: (517) 483-1852

Email: beham@lcc.edu

Alzheimer's Association

(800) 272-3900

A. Knowledge of Disorders

Books

Lippincott, Williams & Wilkins, Inc. (1987 to Present). **Alzheimer's disease & associated disorders: an international journal.** Hagerstown, MD.

National Institute on Aging. (2002). **Alzheimer's disease: unraveling the mystery.** Bethesda, MD.

Powell, L. S. & Courtice, K. (2002). **Alzheimer's disease: a guide for families.** (3rd ed.). Cambridge, MA: Perseus Publishing.

Prime National Publishing Corporation. (2000 to Present). **American journal of Alzheimer's disease and other dementias.** Weston, MA: Prime National Publishing Corporation.

Radin, L. & Radin, G. (Eds.). (2003). **What if it's not Alzheimer's: a caregiver's guide to dementia.** Amherst, NY: Prometheus Books.

Shenk, D. (2003). **The forgetting: Alzheimer's, portrait of an epidemic.** New York, NY: Anchor Books.

Videos

Educational Media Services. (1998). **From here to hope.** [Video.] Durham, NC.

Films for the Humanities & Sciences. (2003). **Alzheimer's mystery.** [Video.] Princeton, NJ.

George G. Glenner Alzheimer's Family Centers, Inc. (1999). **Living in Alzheimer's disease.** [Video.] San Diego, CA.

Geriatric Resources. (1995). **Understanding Alzheimer's disease: an overview from A - Z.** [Video.] Radium Springs, NM.

Info Vision. (1996). **Alzheimer's disease: at time of diagnosis.** [Video.] Glenwood, IA

Long Island Alzheimer's Foundation. (1993). **Living with Alzheimer's.** [Video.] Port Washington, NY.

Terra Nova Films. (2001 b). **String worms at Budd Terrace.** [Video, 71 minutes.] Chicago, IL.

Terra Nova Films. (1990). **Alzheimer's disease: pieces of the puzzle.** [Video.] Chicago, IL.

Twin Cities Public Television, Inc. (2003). **The forgetting.** [Video.] St. Paul, MN.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (a) **Alzheimer's disease**
- (b) **Basics of Alzheimer's**

Weaverdyck, S. **Caring sheets: thoughts & suggestions for caring,** edited and produced by EMU Huron Woods Alzheimer's Research Program for the Michigan Department of Community Health. Available on the Mental Health and Aging Project webpage: <http://www.lcc.edu/mhagp/>

- # 1: **The Healthy Brain and Cognition:** S. Weaverdyck
- # 2: **Brain Changes and the Effects on Cognition:** S. Weaverdyck
- #21: **Questions about a Person's Cognition: An Assessment Checklist:** S. Weaverdyck

B. Person-Centered Care

Books

Amado, A. & McBride, M. (2001). **Training person-centered planning facilitators: A compendium of ideas.** Minneapolis, MN: Institute on Community Integration, University of Minnesota.

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

Barnett, E. (2000). **Including the person with dementia in designing and delivering care: I need to be me!** London; Philadelphia: Jessica Kingsley Publishers.

Center for Health Law and Ethics. **Values history.** Albuquerque, NM: Institute for Public Law, University of New Mexico.

Cobble Hill Health Center, Inc. (1998). **Speaking from experience: Nursing Assistants share their knowledge of dementia care.** Call (718) 855-6789 X225 to obtain order form.

Daly, G., Westphal, C. & Felt, J. (2004). **My voice – my choice: my advance directive package.** Dearborn, MI: Clinical Ethics Center, Oakwood Healthcare System.

Fazio, S., Seman, D. & Stansell, J. (1999). **Rethinking Alzheimer's care.** Baltimore, MD: Health Professions Press.

Innes, A. (Ed.). (2003). **Dementia care mapping: applications across cultures.** Baltimore, MD: Health Professions Press.

Kitwood, T. (1997). **Dementia reconsidered: the person comes first.** Philadelphia, PA: Open University Press.

Ramone, V. (1997). **Caregiving across cultures: working with dementing illness and ethnically diverse populations.** Washington, DC: Taylor & Francis.

Volicer, L & Bloom-Charette, L. (1999). **Enhancing the quality of life in advanced dementia.** Philadelphia, PA: Brunner/Mazel.

Zgola, J. (1999). **Care that works: a relationship approach to persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

Videos

Aging Services Bureau, Dept. of Public Health & Human Services. (1996). **Memory loss among American Indians: the caregiving experience.** [Video.] Helena, MT.

Terra Nova Films. (1995). **Alzheimer's disease: inside looking out.** [Video, 20 minutes]. Chicago, IL.

Terra Nova Films. (1993). **Alzheimer's disease: a multi-cultural perspective.** [Video.] Chicago, IL.

Terra Nova Films. (1992). **Early onset memory loss: a conversation with Letty Tennis.** [Video, 20 minutes.] Chicago, IL.

TMK Productions. (2002). **Facing Alzheimer's: an African-American perspective.** [Video.] Northfield, IL.

Video Press. (1991). **Grace.** [Video, 58 minutes.] Baltimore, MD.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (h) **Depression and Alzheimer's disease**
- (j) **Driving**
- (l) **Feelings (also available in Spanish)**
- (r) **Respect for Autonomy**

C. Care Interactions

Books

Andresen, G. (1995). **Caring for people with Alzheimer's disease**. Baltimore, MD: Health Professions Press, Inc.

Barrick, A. (2002). **Bathing without a battle: Personal care of individuals with dementia**. New York: Springer Pub.

Bell, V., & Troxel, D. (2003). **The Best Friends approach to Alzheimer's care**. Baltimore, MD: Health Professions Press, Inc.

Calkins, M. (2001). **Creating successful dementia care settings**. Baltimore, MD: Health Professions Press.

Cobble Hill Health Center, Inc. (1998). **Speaking from experience: Nursing Assistants share their knowledge of dementia care**. Call (718) 855-6789 X225 to obtain order form.

Feil, N. (2002). **The validation breakthrough: simple techniques for communicating with people with Alzheimer's type dementia**. (2nd ed.). Baltimore, MD: Health Professions Press.

Gwyther, L. (2001). **Caring for people with Alzheimer's disease: a manual for facility staff**. Chicago, IL: Alzheimer's Association. Available from the Alzheimer's Association, (800) 223- 4405, order no. ED554Z.

Hellen, C. (1998). **Alzheimer's disease: activity-focused care**. (2nd ed.). St. Louis, MO: Butterworth-Heinemann.

Hudson, R., & Theol, M. (Eds.) (2003). **Dementia nursing: a guide to practice**. Baltimore, MD: Health Professions Press.

Jones, M. (1999). **Gentlecare: changing the experience of Alzheimer's disease in a positive way**. Point Roberts, WA: Hartley & Marks.

Kuhn, D. (2003). **Alzheimer's early stages: first steps for families, friends and caregivers**. (2nd ed.). Alameda, CA: Hunter House Publishers.

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

Lawton, M. P. & Rubinstein, R. L. (Eds.). (2000). **Interventions in dementia care: toward improving quality of life.** New York, NY: Springer Publishing Co.

Mace, N., Coons, D. & Weaverdyck S. (2005). **Teaching dementia care: skill and understanding.** Baltimore, MD: Johns Hopkins University Press.

Mace, N. & Rabins, P. (1999). **The 36-hour day: a family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life.** (3rd ed.). Baltimore, MD: Johns Hopkins University Press.

Robinson A, Spencer B, White L. (2002). **Understanding difficult behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses.** Ypsilanti, MI: Alzheimer's Education Program, Eastern Michigan University, 734-487-2335, www.emich.edu/alzheimers.

White, L. & Spencer, B. (2000). **Moving a relative with memory loss; a family caregiver's guide.** Santa Rosa, CA: Whisp Publications.

Videos

Alzheimer's Association, Desert Southwest Chapter. (2004). **Palliative care for advanced dementia: a self-instructional seven-part teaching program.** [Video.] Phoenix, AZ.

Eastern Michigan University Huron Woods Alzheimer's Research Program. (2001). **Assisting a person with dementia in bathing.** [Video]. Mental Health and Aging Project, Michigan Partnership for Community Caring.

Edward Feil Productions. (1991). **Communicating with the Alzheimer's-type population: the validation method.** [Video].

Terra Nova Films. (1999). **He's doing this to spite me: emotional conflicts in dementia care.** [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1998). **Choice and challenge: caring for aggressive older adults across levels of care.** [Video and manual.] Chicago, IL.

Terra Nova Films. (1997). **Recognizing and responding to emotion in persons with dementia.** [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1990 a). **Assisting the nursing home resident with Alzheimer's disease: a day in the life of Nancy Moore.** [Video, 25 minutes.] Chicago, IL.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (a) **Alzheimer's disease**
- (g) **Communication**
- (i) **Dressing** (also available in Spanish)
- (k) **Eating** (also available in Spanish)
- (o) **Incontinence** (also available in Spanish)
- (p) **Late stage care**
- (q) **Personal care**
- (s) **Safety** (also available in Spanish)
- (t) **Safety at home**
- (u) **Sleep changes in Alzheimer's disease**
- (v) **Sexuality**

Weaverdyck, S. **Caring sheets: thoughts & suggestions for caring**, edited and produced by EMU Huron Woods Alzheimer's Research Program for the Michigan Department of Community Health. Available on the Mental Health and Aging Project webpage: <http://www.lcc.edu/mhap/>

- # 4: **Moving Persons with Dementia? Suggestions for the Physical Environment to Ease the Way:** D. deLaski-Smith
- # 5: **Moving Persons with Dementia? Suggestions for Family and Staff to Ease the Way:** L. Struble & D. deLaski-Smith
- # 6: **Moving Persons with Dementia? Tips Regarding Behaviors to Ease the Way:** L. Struble
- # 7: **The Bedroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 8: **The Bathroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 9: **Resources: The Physical Environment:** D. deLaski-Smith
- #10: **Communicating with Health Care Providers:** A. Wittle & S. Weaverdyck
- #14: **Helping with Daily Tasks:** S. Weaverdyck
- #17: **Safety after Hip Surgery: Tips for Preventing Complications:** B. Atchison
- #18: **Transferring Persons with Dementia:** D. Dirette
- #19: **Intervention Suggestions for Frontal Lobe Impairment:** S. Weaverdyck
- #22: **Questions about the Environment: An Assessment Checklist:** S. Weaverdyck
- #23: **Questions about Caregiving: An Assessment Checklist:** S. Weaverdyck
- #24: **Questions about the Task & Daily Routines: An Assessment Checklist:** S. Weaverdyck

D. Life Enrichment Support

Books

Ballard, E. & Poer, C. (1993). **Sexuality and the Alzheimer's patient**. Durham, NC: Alzheimer's Family Support Program, Center for Aging, Duke University.

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

Dowling, J. (1995). **Keeping busy: a handbook of activities for persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

Hellen, C. (1998). **Alzheimer's disease: activity-focused care.** (2nd ed.). St. Louis, MO: Butterworth-Heinemann.

Kubler-Ross, E. & Kessler, D. (2000). **Life lessons: two experiences of death and dying teach us about the mysteries of life and living.** New York, NY: Scribner.

Sheridan, C. (1987). **Failure-free activities for the Alzheimer patient: a guidebook for caregivers.** Forest Knolls, CA: Elder Books.

Zgola, J., OTC. (1997). Programming. In **Key elements of dementia care.** Chicago, IL: Alzheimer's Association National Office, (800) 223- 4405.

Videos

Terra Nova Films. (1995 c). **Thousand tomorrows: intimacy, sexuality and Alzheimer's.** [Video.] Chicago, IL.

Terra Nova Films. (1993). **Alzheimer's disease: a multi-cultural perspective.** [Video.] Chicago, IL.

Video Press. (1996). **Dealing with sexually inappropriate behavior: masturbation and sexually provocative behavior.** [Video.] Baltimore, MD.

Video Press. (1996 a). **Dealing with sexually inappropriate behavior: physical touching and disrobing.** [Video.] Baltimore, MD.

Video Press. (1993 b). **Sleep, sex, and wandering.** [Video.] Baltimore, MD. Phone: (800) 328-7450 or <http://www.videopress.org>.

E. Understanding Behaviors

Books

Hoffman, S. & Kaplan, M. (1998). **Behaviors in dementia: best practices for successful management.** Baltimore, MD: Health Professions Press.

Robinson A, Spencer B, White L. (2002). **Understanding difficult behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses.** Ypsilanti, MI: Alzheimer's Education Program, Eastern Michigan University, 734-487-2335, www.emich.edu/alzheimers.

Silverstein, N., Flaherty, G. & Tobin, T. (2002). **Dementia and wandering behavior: concern for the lost elder.** New York, NY: Springer Publishing Company.

Soreff, S. & Siddle, D. (2004). Understanding and dealing with resident aggression: exploring the extent, causes, and impact of aggressive outbursts and how to handle them. *Nursing Homes Long Term Care Management*. March.

Videos & DVDs

Advanced Healthcare Studies. (2003). **Sundowning: a caregiver's guide**. [Video.] San Marcos, CA. Phone: (800) 444-1384 or <http://www.advhs.com>.

Alzheimer's Association. (2005). **Behavior management training for dementia care by the Alzheimer's Association NY chapters**. [DVD]. This interactive DVD can be at www.alzwny.org or www.alzcnny.org.

Eastern Michigan University Huron Woods Alzheimer's Research Program. (2001). **Assisting a person with dementia in bathing**. [Video.] Mental Health and Aging Project, Michigan Partnership for Community Caring.

Fanlight Productions. (1998). **Alzheimer's and dementia care skills for assisted living**. [Videos.] Boston, MA.

Wandering: is it a problem? (14 minutes).

Resisting Care...putting yourself in their shoes (14 minutes).

Agitation...it's a sign (14 minutes).

Terra Nova Films. (1998). **Choice and challenge: caring for aggressive older adults across levels of care**. [Video and manual.] Chicago, IL.

Terra Nova Films. (1993 c). **Dress him while he walks: management in caring for residents with Alzheimer's**. [Video.] Chicago, IL.

Terra Nova Films. (1990 b). **Managing and understanding behavior problems in Alzheimer's**. [Video.] Chicago, IL.

University of North Carolina at Chapel Hill. (2003). **Bathing without a battle: creating a better bathing experience for persons with Alzheimer's disease and related disorders**. [1 hour video / 2 to 3 hour CD.] Chapel Hill, NC. *NOTE: This program is powerful and graphic and is not recommended for nonprofessionals or families.*

Video Press. (2002). **Abuse triggers**. [6 videos.] Baltimore, MD:

Incontinence and Other Physical Problems (16 minutes).

The Non-Responsive Needy Resident (16 minutes).

Physical Violence (16 minutes).

Repetitive Behavior (17 minutes).

Resistive Behavior (17 minutes).

Verbal Violence (19 minutes).

Video Press. (2001). **Abuse and the dementia patient**. [Video, 22 minutes.] Baltimore, MD.

Video Press. (1997 a). **Preventing and reducing negative and abusive responses.** [Video.] Baltimore, MD.

Video Press. (1993). **Paranoia, suspiciousness and accusations.** [Video.] Baltimore, MD.

Video Press. (1993 a). **Positive approaches to difficult behaviors.** [Video.] Baltimore, MD.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (d) **Behavioral and psychiatric Alzheimer symptoms**
- (e) **Behaviors**
- (n) **Hallucinations.**

F. Interacting with Families

Books

Bayley, J. (1999). **Elegy for Iris.** New York, NY: St. Martin's Press.

Benedicts, T. Jaffe, J., Segal, J. (2004). **Elder abuse: types, signs, symptoms, causes, and help.** Retrieved August, 14, 2006 from http://www.helpguide.org/mental/elder_abuse_physical_emotional_sexual_neglect.htm.

Bryden, C. (2005). **Dancing with dementia: my story of living positively with Dementia.** Philadelphia, PA: Jessica Kingsley Publishers.

Coon, D., Gallagher-Thompson, D. & Thompson, L. (2003). **Innovative interventions to reduce dementia caregiver distress: a clinical guide.** New York, NY: Springer Publishing Co.

Hay, D. (Ed.). (2003). **Agitation in patients with dementia: a practical guide to diagnosis and management.** Washington, DC: American Psychiatric Pub.

Knight, B. (2001). **Blessed are the caregivers: a daily book of comfort and cheer.** Albuquerque, NM: Hartman Publishing, Inc.

Mahoney, E., Volicer, L. & Hurley, A. (2000). **Management of challenging behaviors in dementia.** Baltimore, MD: Health Professions Press.

Mittelman, M., Epstein, C. & Pierzchala A. (2003). **Counseling the Alzheimer caregiver: a resource for health care professionals.** Chicago, IL: American Medical Association Press.

Murphy, B. (1995). **He used to be somebody: a journey into Alzheimer's disease through the eyes of a caregiver.** Boulder, CO: Gibbs Associates.

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

Videos

Alzheimer's Association National Office. (1990 a). **Caring for the caregiver** [Video, 20 minutes, part of Caregiver Kit]. Chicago, IL. (800) 223-4405.

Terra Nova Films. (2001 b). **String worms at Budd Terrace**. [Video, 71 minutes.] Chicago, IL.

Terra Nova Films. (1999). **He's doing this to spite me: emotional conflicts in dementia care**. [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1995 c). **Thousand tomorrows: intimacy, sexuality and Alzheimer's**. [Video.] Chicago, IL.

Terra Nova Films. (1994 a). **Complaints of a dutiful daughter**. [Video, 44 minutes.] Chicago, IL.

Terra Nova Films. (1993). **Alzheimer's disease: a multi-cultural perspective**. [Video.] Chicago, IL.

Video Press. (1991). **Grace**. [Video, 58 minutes.] Baltimore, MD.

Fact Sheets

Alzheimer's Association Fact Sheets*

(f) **Caregiver stress**. Available in Spanish.

(m) **Grief, mourning and guilt**. Available in Spanish.

G. Direct Care Worker Self Care

Books

Kramer, N. & Smith, M. (2003). **Working together: nursing assistants help one another manage stress in the workplace**. Download it at www.sephardichome.org or contact Nanette A. Kramer at nk105@columbia.edu.

Parke-Davis A Division of Warner-Lambert Company. (1994). **Caring for the Caregiver: a guide to living with Alzheimer's disease**.

Ruckdeschel, K. & Van Haitsma, K. (2001). **Building relationships to enhance resident-centered care: a trainer's guide to an emotion-focused intervention**. Contact the Harry Stern Family Center for Innovations in Alzheimer's Care (215) 371-1890, or the Extencicare Foundation.

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

Videos

Paraprofessional Institute in Philadelphia. (2001). **HeartWork**. [Video.] Available through the National Clearinghouse on the Direct Care Workforce, Bronx, NY.

Terra Nova. (1992 a). **Working it out: support groups for nursing home aids**. [Video.] Chicago, IL.

Video Press. (1990). **Caregiver stress in long-term care**. [Video, 20 minutes.] Baltimore, MD.



References

Advanced Healthcare Studies. (2003). **Sundowning: a caregiver's guide.** [Video.] San Marcos, CA. Phone: (800) 444-1384 or <http://www.advhs.com>.

Aging Services Bureau, Department of Public Health & Human Services. (1996). **Memory loss among American Indians: the caregiving experience.** [Video.] Helena, MT.

Alzheimer's Association. Fact sheets and brochures available at www.alz.org or call 1-800-272-3900. Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website.

- (a) **Alzheimer's disease**
- (b) **Basics of Alzheimer's**
- (c) **Bathing.** Available in Spanish.
- (d) **Behavioral and psychiatric Alzheimer symptoms**
- (e) **Behaviors**
- (f) **Caregiver stress.** Available in Spanish.
- (g) **Communication**
- (h) **Depression and Alzheimer's disease**
- (i) **Dressing.** Available in Spanish.
- (j) **Driving**
- (k) **Eating.** Available in Spanish.
- (l) **Feelings.** Available in Spanish.
- (m) **Grief, mourning and guilt.** Available in Spanish.
- (n) **Hallucinations.**
- (o) **Incontinence.** Available in Spanish.
- (p) **Late stage care.**
- (q) **Personal care.**
- (r) **Respect for Autonomy**
- (s) **Safety.** Available in Spanish
- (t) **Safety at home.**
- (u) **Sleep changes in Alzheimer's disease**
- (v) **Sexuality.**

Alzheimer's Association. (2005). **Behavior management training for dementia care by the Alzheimer's Association NY chapters.** [Video.] This interactive DVD can be obtained at www.alzwny.org or www.alzcnv.org.

Alzheimer's Association, Desert Southwest Chapter. (2004). **Palliative care for advanced dementia: a self-instructional seven-part teaching program.** [Video.] Phoenix, AZ.

Alzheimer's Association, Los Angeles Chapter. (1998). **Diagnosis and management of persons with dementia.** [Video.] Los Angeles, CA.

Alzheimer's Association National Office. (1990). **Caregiver kit.** Chicago, IL.

Alzheimer's Association National Office. (1990 a). **Caring for the caregiver** [Video, 20 minutes, part of Caregiver Kit.] Chicago, IL. (800) 223-4405.

Alzheimer's Association, Western New York Chapter. (2001). **Managing nutrition in dementia care: a supportive approach for caregivers**. Depew, NY. To purchase email matthew.lorigo@alz.org or call the Alzheimer's Association at 1-800-273-6737.

Alzheimer Society of Canada. (1998). **Alzheimer's journey**. [Video.] Toronto, Canada.

Amado, A. & McBride, M. (2001). **Training person-centered planning facilitators: A compendium of ideas**. Minneapolis, MN: University of Minnesota, Institute on Community Integration.

Andresen, G. (1995). **Caring for people with Alzheimer's disease**. Baltimore, MD: Health Professions Press, Inc.

Aspen Publishers. (1995). **Home care for people with Alzheimer's disease**. [Video.] Gaithersburg, MD.

Aspen Publishers. (2000 to present). **Alzheimer's care quarterly**. Frederick, MD.

Ballard, E. & Poer, C. (1993). **Sexuality and the Alzheimer's patient**. Durham, NC: Alzheimer's Family Support Program, Center for Aging, Duke University.

Barnett, E. (2000). **Including the person with dementia in designing and delivering care: I need to be me!** London; Philadelphia: Jessica Kingsley Publishers.

Barrick, A. (2002). **Bathing without a battle: Personal care of individuals with dementia**. New York: Springer Pub.

Bayley, J. (1999). **Elegy for Iris**. New York, NY: St. Martin's Press.

Beedle, J. (1991). **Carebook: a workbook for caregiver peace of mind**. San Carlos, CA: Lady Bug Press.

Bell, V., & Troxel, D. (2003). **The Best Friends approach to Alzheimer's care**. Baltimore, MD: Health Professions Press, Inc.

Bell, V. & Troxel, D. (2002). **A dignified life: The Best Friends approach to Alzheimer's care, a guide for family caregivers**. Deerfield Beach, FL: Health Communications, Inc.

Bell, V. & Troxel, D. (2001). **The Best Friends staff; building a culture of care in Alzheimer's programs**. Baltimore, MD: Health Professions Press, Inc.

Benedicts, T. Jaffe, J., Segal, J. (2004). **Elder abuse: types, signs, symptoms, causes, and help**. Retrieved August, 14, 2006 from http://www.helpguide.org/mental/elder_abuse_physical_emotional_sexual_neglect.htm.

Brawley, E. (1997). **Designing for Alzheimer's disease: strategies for creating better care environments**. New York, NY: John Wiley & Sons, Inc.

Bridges, B. (1996). **Therapeutic caregiving: a practical guide for caregivers of persons with Alzheimer's and other dementia causing diseases**. Mill Creek, WA: BJB Publishing.

Bryan, J. (2002). **Love is ageless: stories about Alzheimer's disease**. Felton, CA: Lompico Creek Press.

- Bryden, C. (2005). **Dancing with dementia: my story of living positively with dementia**. Philadelphia, PA: Jessica Kingsley Publishers.
- Calkins, M. (2001). **Creating successful dementia care settings**. Baltimore, MD: Health Professions Press.
- Castleman, M., Gallagher-Thompson, D. & Naythons, M. (1999). **There's still a person in there: The complete guide to treating and coping with Alzheimer's**. New York: Putnam.
- Center for Health Law and Ethics. **Values history**. Albuquerque, NM: Institute for Public Law, University of New Mexico.
- Cobble Hill Health Center, Inc. (1998). **Speaking from experience: Nursing Assistants share their knowledge of dementia care**. Call (718) 855-6789 X225 to obtain order form.
- Coon, D., Gallagher-Thompson, D. & Thompson, L. (2003). **Innovative interventions to reduce dementia caregiver distress: a clinical guide**. New York, NY: Springer Publishing Co.
- Coste, J. (2003). **Learning to speak Alzheimer's: a groundbreaking approach for everyone dealing with the disease**. New York, NY: First Mariner Books.
- Daly, G., Westphal, C. & Felt, J. (2004). **My voice-my choice: my advance directive package**. Dearborn, MI: Clinical Ethics Center, Oakwood Healthcare System.
- Davidson, A. (1997). **Alzheimer's, a love story: one year in my husband's journey**. Secaucus, NJ: Carol Pub. Group.
- Davis, R. (1989). **My journey into Alzheimer's disease: a true story**. Wheaton, IL: Tyndale House Publishers.
- DeBaggio, T. (2002). **Losing my mind: an intimate look at life with Alzheimer's**. New York, NY: Free Press.
- Dippel, R. (1996). **Caring for the Alzheimer patient: a practical guide**. Amherst, NY: Prometheus Books.
- District of Columbia Office on Aging. (2000). **Alone but not forgotten: serving people with dementia who live alone**. [Video.] Available only from Duke University Media Services – Medical Center, 919-681-2483.
- Dowling, J. (1995). **Keeping busy: a handbook of activities for persons with dementia**. Baltimore, MD: Johns Hopkins University Press.
- Eastern Michigan University Huron Woods Alzheimer's Research Program. (2001). **Assisting a person with dementia in bathing**. [Video.] Mental Health and Aging Project, Michigan Partnership for Community Caring.
- Edward Feil Productions. (1991). **Communicating with the Alzheimer's-type population: the validation method**. [Video.]

Educational Media Services. (1998). **From here to hope.** [Video.] Durham, NC.

Fanlight Productions. (1998). **Alzheimer's and dementia care skills for assisted living.** [Video.] Boston, MA.

Wandering: is it a problem? (14 minutes).

Resisting Care...putting yourself in their shoes (14 minutes).

Agitation...it's a sign (14 minutes).

Fazio, S., Seman, D. & Stansell, J. (1999). **Rethinking Alzheimer's care.** Baltimore, MD: Health Professions Press.

Feil, N. (2002). **The validation breakthrough: simple techniques for communicating with people with Alzheimer's type dementia.** (2nd ed.). Baltimore, MD: Health Professions Press.

Films for the Humanities & Sciences. (2003). **Alzheimer's mystery.** [Video.] Princeton, NJ.

Films for the Humanities and Sciences, (2000). **On our own terms – Moyers on dying in America.** [Video.] Princeton, NJ.

George G. Glenner Alzheimer's Family Centers, Inc. (1999). **Living in Alzheimer's disease.** [Video.] San Diego, CA.

Geriatric Resources. (1995). **Understanding Alzheimer's disease: an overview from A - Z.** [Video] Radium Springs, NM.

Gibson, F. (2004). **The past in the present: using reminiscence in health and social care.** Baltimore, MD: Health Professions Press.

Gruetzner, H. (2001). **Alzheimer's: the caregiver's guide and sourcebook.** (3rd ed.). New York, NY: John Wiley & Sons, Inc.

Gwyther, L. (2001). **Caring for people with Alzheimer's disease: a manual for facility staff.** Chicago, IL: Alzheimer's Association. Available from the Alzheimer's Association, (800) 223- 4405, order no. ED554Z.

Hamdy, R. (1998). **Alzheimer's disease: a handbook for caregivers.** St. Louis, MO: Mosby.

Hay, D. (Ed.). (2003). **Agitation in patients with dementia: a practical guide to diagnosis and management.** Washington, DC: American Psychiatric Pub.

Hellen, C. (1998). **Alzheimer's disease: activity-focused care.** (2nd ed.). St. Louis, MO: Butterworth-Heinemann.

Henderson, C. (1998). **Partial view: an Alzheimer's journal.** Dallas, TX: Southern Methodist University Press.

Hoffman, S. & Kaplan, M. (1998). **Behaviors in dementia: best practices for successful management.** Baltimore, MD: Health Professions Press.

Hoffman, S. & Platt, C. (1991). **Comforting the confused, strategies for managing dementia.** (2nd ed.). New York: Springer Pub. Co.

Hospice of Michigan. (2005). **Caring for a loved one with advanced dementia: a caregiver's manual.** (2nd ed.). Detroit, MI. Hospice of Michigan. 1-888-466-5656 or www.hom.org.

Hudson, R., & Theol, M. (Eds.) (2003). **Dementia nursing: a guide to practice.** Baltimore, MD: Health Professions Press.

Independent Production Fund. (1995). **Everyone wins! quality care without restraints.** [Video.] New York, NY.

Info Vision. (1996). **Alzheimer's disease: at time of diagnosis.** [Video.] Glenwood, IA.

Innes, A. (Ed.). (2003). **Dementia care mapping: applications across cultures.** Baltimore, MD: Health Professions Press.

Johns Hopkins University Press. (1996). **Training manual and video for dementia care specialists.** Baltimore, MD.

Jones, M. (1999). **Gentlecare: changing the experience of Alzheimer's disease in a positive way.** Point Roberts, WA: Hartley & Marks.

Kessler, D. (1997). **The needs of the dying: a guide for bringing hope, comfort and love to life's final chapter.** New York, NY: HarperCollins Publisher.

Killick, J. & Cordonner, C. (Eds.). (2000). **Openings: dementia poems and photographs.** London: Hawker Publications. <http://www.careinfo.org/books/>.

Kitwood, T. (1997). **Dementia reconsidered: the person comes first.** Philadelphia, PA: Open University Press.

Knight, B. (2001). **Blessed are the caregivers: a daily book of comfort and cheer.** Albuquerque, NM: Hartman Publishing, Inc.

Kovach, C. (Ed.). (1997). **Late-stage dementia care: a basic guide.** Washington, DC: Taylor & Francis.

Kramer, N. & Smith, M. (2003). **Working together: nursing assistants help one another manage stress in the workplace.** Download it at www.sephardichome.org or contact Nanette A. Kramer at nk105@columbia.edu.

Kubler-Ross, E. & Kessler, D. (2000). **Life lessons: two experiences of death and dying teach us about the mysteries of life and living.** New York, NY: Scribner.

Kuhn, D. (2003). **Alzheimer's early stages: first steps for families, friends and caregivers.** (2nd ed.). Alameda, CA: Hunter House Publishers.

Lawton, M. P. & Rubinstein, R. L. (Eds.). (2000). **Interventions in dementia care: toward improving quality of life.** New York, NY: Springer Publishing Co.

Lippincott, Williams & Wilkins, Inc. (1987 to Present). **Alzheimer's disease & associated disorders: an international journal.** Hagerstown, MD.

Long Island Alzheimer's Foundation. (1993). **Living with Alzheimer's.** [Video.] Port Washington, NY.

Lustbader, W. & Hooyman, N. (1994). **Taking care of aging family members, a practical guide.** New York, NY: The Free Press, a Division of Macmillan, Inc.

Mace, N., Coons, D. & Weaverdyck S. (2005). **Teaching dementia care: skill and understanding.** Baltimore, MD: Johns Hopkins University Press.

Mace, N. & Rabins, P. (1999). **The 36-hour day: a family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life.** (3rd ed.). Baltimore, MD: Johns Hopkins University Press.

Mahoney, E., Volicer, L. & Hurley, A. (2000). **Management of challenging behaviors in dementia.** Baltimore, MD: Health Professions Press.

Meyer, M. & Derr, P. (1998). **The comfort of home.** Portland, Oregon: CareTrust Publications, LLC.

Midwest Bio-Ethics Center. **Midwest Bio-ethics Center caring conversations workbook.** Kansas City, MO. 816-221-1100. www.midbio.org. (Discusses how people can make known their wishes for end-of-life care.)

Mittelman, M., Epstein, C. & Pierzchala A. (2003). **Counseling the Alzheimer caregiver: a resource for health care professionals.** Chicago, IL: American Medical Association Press.

Morris, V. (1996). **How to care for aging parents.** New York, NY: Workman Publishing Company, Inc.

Murphy, B. (1995). **He used to be somebody: a journey into Alzheimer's disease through the eyes of a caregiver.** Boulder, CO: Gibbs Associates.

National Institute on Aging. (2002). **Alzheimer's disease: unraveling the mystery.** Bethesda, MD.

Northeast Health Care Quality Foundation. (2006). **Reclaiming the magic of caring: the path and process for individualizing care.** The Quality Improvement Organization for Maine, New Hampshire and Vermont. NHQI participant group workshop #4. 0506-543.1
http://www.nhcqf.org/QI_Services/NursingHomes/Workshop4/Rader_Slides_Part_3_0506-543.1.pdf.

Paraprofessional Institute in Philadelphia. (2001). **HeartWork.** [Video.] Bronx, NY: National Clearinghouse on the Direct Care Workforce.

Parke-Davis A Division of Warner-Lambert Company. (1994). **Caring for the Caregiver: a guide to living with Alzheimer's disease.** PD-102-BK-8645-A290449404309.

Phair, L. & Good, V. (1998). **Dementia: a positive approach.** London: Whurr Publishers.

Pietro, Cook & Ostuni. (2003). **Successful communication with persons with Alzheimer's disease: an in-service manual.** St. Louis, MO: Butterworth-Heinemann.

Powell, L. S. & Courtice, K. (2002). **Alzheimer's disease: a guide for families.** (3rd ed.). Cambridge, MA: Perseus Publishing.

Prime National Publishing Corporation. (2000 to Present). **American journal of Alzheimer's disease and other dementias.** Weston, MA.

Primedia Workplace Learning. (1999). **Communicating with older adults and people with dementia, part one.** [Video, 42 minutes.] Carrollton, TX.

Rader, J. (1995). **Individualized dementia care: creative, compassionate approaches.** (E. M. Tomquist, Ed.). New York, NY: Springer Publishing Co.

Radin, L. & Radin, G. (Eds.). (2003). **What if it's not Alzheimer's: a caregiver's guide to dementia.** Amherst, NY: Prometheus Books.

Ramone, V. (1997). **Caregiving across cultures: working with dementing illness and ethnically diverse populations.** Washington, DC: Taylor & Francis.

Robinson A, Spencer B, White L. (2002). **Understanding difficult behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses.** Ypsilanti, MI: The Alzheimer's Education Program, Eastern Michigan University. 734-487-2335, www.emich.edu/alzheimers.

Ruckdeschel, K. & Van Haitsma, K. (2001). **Building relationships to enhance resident-centered care: a trainer's guide to an emotion-focused intervention.** The Harry Stern Family Center for Innovations in Alzheimer's Care, (215) 371-1890, or the Extencicare Foundation.

Shenk, D. (2003). **The forgetting: Alzheimer's, portrait of an epidemic.** New York, NY. Anchor Books.

Sheridan, C. (1987). **Failure-free activities for the Alzheimer patient: a guidebook for caregivers.** Forest Knolls, CA: Elder Books.

Silverstein, N., Flaherty, G. & Tobin, T. (2002). **Dementia and wandering behavior: concern for the lost elder.** New York, NY: Springer Publishing Company.

Silverstone, B. & Kandel-Hyman, H. (1989). **You and your aging parent: The modern family's guide to emotional, physical, and financial problems.** (2nd rev. ed.). New York, NY: Pantheon Books.

Simpson, C. (1996). **At the heart of Alzheimer's.** Gaithersburg, MD: Manor Healthcare Corp.

Soreff, S. & Siddle, D. (2004). Understanding and dealing with resident aggression: exploring the extent, causes, and impact of aggressive outbursts and how to handle them. **Nursing Homes Long Term Care Management.** March.

South Carolina Educational Television. (1993). **Alzheimer's 101: the basics for caregiving.** [Video.] Columbia, SC.

Stobbe, K. (2002). **Sometimes ya gotta laugh: caregiving, laughter, stress and Alzheimer's disease.** [Video and book.] Contact author: Karen Stobbe, 828-357-8023, karenstobbe@charter.net.

Terra Nova Films. (2003). **Dementia with dignity.** [Video.] Chicago, IL.

Terra Nova Films. (2003 a). **More than a thousand tomorrows**. [Video.] Chicago, IL.

Terra Nova Films. (2002). **Pain management in long-term care: case studies**. [Video.] Chicago, IL.

Terra Nova Films. (2001). **Bon appetite: how to create meaningful mealtimes in long-term care**. [Video.] Chicago, IL.

Terra Nova Films. (2001 a). **Injury prevention / preventing choking and aspiration**. [Video.] Chicago, IL.

Terra Nova Films. (2001 b). **String worms at Budd Terrace**. [Video, 71 minutes.] Chicago, IL.

Terra Nova Films. (1999). **He's doing this to spite me: emotional conflicts in dementia care**. [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1998). **Choice and challenge: caring for aggressive older adults across levels of care**. [Video and manual.] Chicago, IL.

Terra Nova Films. (1997). **Recognizing and responding to emotion in persons with dementia**. [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1996). **Solving bathing problems with Alzheimer's disease and related disorders**. [Video.] Chicago, IL. *NOTE: This program is powerful and graphic and is not recommended for nonprofessionals or family viewing.*

Terra Nova Films. (1995). **Alzheimer's disease: inside looking out**. [Video, 20 minutes.] Chicago, IL.

Terra Nova Films. (1995 a). **Compassionate touch: benefits and effects in Alzheimer's care**. [Video, 27 minutes.] Chicago, IL.

Terra Nova Films. (1995 b). **In your hands -- nursing home resident care**. [Video.] Chicago, IL.

Terra Nova Films. (1995 c). **Thousand tomorrows: intimacy, sexuality and Alzheimer's**. [Video.] Chicago, IL.

Terra Nova Films. (1994). **Caregiver's guide to oral health**. [Video.] Chicago, IL.

Terra Nova Films. (1994 a). **Complaints of a dutiful daughter**. [Video, 44 minutes.] Chicago, IL.

Terra Nova Films. (1993). **Alzheimer's disease: a multi-cultural perspective**. [Video.] Chicago, IL.

Terra Nova Films. (1993 a). **Alzheimer's disease: natural feeding techniques**. [Video.] Chicago, IL.

Terra Nova Films. (1993 b). **Best friends**. [Video, 14 minutes.] Chicago, IL.

Terra Nova Films. (1993 c). **Dress him while he walks: management in caring for residents with Alzheimer's**. [Video.] Chicago, IL.

Terra Nova Films. (1992). **Early onset memory loss: a conversation with Letty Tennis.** [Video, 20 minutes.] Chicago, IL.

Terra Nova. (1992 a). **Working it out: support groups for nursing home aids.** [Video.] Chicago, IL.

Terra Nova Films. (1990). **Alzheimer's disease: pieces of the puzzle.** [Video.] Chicago, IL.

Terra Nova Films. (1990 a). **Assisting the nursing home resident with Alzheimer's disease: a day in the life of Nancy Moore.** [Video, 25 minutes.] Chicago, IL.

Terra Nova Films. (1990 b). **Managing and understanding behavior problems in Alzheimer's.** [Video.] Chicago, IL.

TMK Productions. (2002). **Facing Alzheimer's: an African-American perspective.** [Video.] Northfield, IL.

Truscott, M. (2003). **Life in the slow lane.** *Alzheimer's Care Quarterly* 4(1): 11-17.

Twin Cities Public Television, Inc. (2003). **The forgetting.** [Video.] St. Paul, MN.

University of North Carolina at Chapel Hill. (2003). **Bathing without a battle: creating a better bathing experience for persons with Alzheimer's disease and related disorders.** [1 hour video / 2 to 3 hour CD.] Chapel Hill, NC. *NOTE: This program is powerful and graphic and is not recommended for nonprofessionals or family viewing.*

Video Press. (2002). **Abuse triggers.** Baltimore, MD.

Incontinence and Other Physical Problems (16 minutes).

The Non-Responsive Needy Resident (16 minutes).

Physical Violence (16 minutes).

Repetitive Behavior (17 minutes).

Resistive Behavior (17 minutes).

Verbal Violence (19 minutes).

Video Press. (2002 a). **Controlling pain.** [Video.] Baltimore, MD.

Video Press. (2001). **Abuse and the dementia patient.** [Video, 22 minutes.] Baltimore, MD.

Video Press. (2001 a). **Is Mrs. Jones OK?** [Video.] Baltimore, MD.

Video Press. (1997). **Alzheimer caregiver kit.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1997 a). **Preventing and reducing negative and abusive responses.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1996). **Dealing with sexually inappropriate behavior: masturbation and sexually provocative behavior.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1996 a). **Dealing with sexually inappropriate behavior: physical touching and disrobing.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1993). **Paranoia, suspiciousness and accusations.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1993 a). **Positive approaches to difficult behaviors.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1993 b). **Sleep, sex, and wandering.** [Video.] Baltimore, MD. (800) 328-7450 or <http://www.videopress.org>.

Video Press. (1991). **Grace.** [Video, 58 minutes.] Baltimore, MD.

Video Press. (1990). **Caregiver stress in long-term care.** [Video, 20 minutes.] Baltimore, MD.

Volicer, L & Bloom-Charette, L. (1999). **Enhancing the quality of life in advanced dementia.** Philadelphia, PA: Brunner/Mazel.

Volicer, L. & Hurley, A. (1998). **Hospice care for patients with advanced progressive dementia.** New York: Springer Pub. Co.

Weaverdyck, S. **Caring sheets: thoughts & suggestions for caring,** edited and produced by EMU Huron Woods Alzheimer's Research Program for the Michigan Department of Community Health. Available on the Mental Health and Aging Project webpage: <http://www.loc.edu/mhap/>

- # 1: **The Healthy Brain and Cognition:** S. Weaverdyck
- # 2: **Brain Changes and the Effects on Cognition:** S. Weaverdyck
- # 4: **Moving Persons with Dementia? Suggestions for the Physical Environment to Ease the Way:** D. deLaski-Smith
- # 5: **Moving Persons with Dementia? Suggestions for Family and Staff to Ease the Way:** L. Struble & D. deLaski-Smith
- # 6: **Moving Persons with Dementia? Tips Regarding Behaviors to Ease the Way:** L. Struble
- # 7: **The Bedroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 8: **The Bathroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 9: **Resources: The Physical Environment:** D. deLaski-Smith
- #10: **Communicating with Health Care Providers:** A. Wittle & S. Weaverdyck
- #14: **Helping with Daily Tasks:** S. Weaverdyck
- #17: **Safety after Hip Surgery: Tips for Preventing Complications:** B. Atchison
- #18: **Transferring Persons with Dementia:** D. Dirette
- #19: **Intervention Suggestions for Frontal Lobe Impairment:** S. Weaverdyck
- #21: **Questions about a Person's Cognition: An Assessment Checklist:** S. Weaverdyck
- #22: **Questions about the Environment: An Assessment Checklist:** S. Weaverdyck
- #23: **Questions about Caregiving: An Assessment Checklist:** S. Weaverdyck
- #24: **Questions about the Task & Daily Routines: An Assessment Checklist:** S. Weaverdyck

White, L. & Spencer, B. (2000). **Moving a relative with memory loss; a family caregiver's guide.** Santa Rosa, CA: Whisp Publications.

Wisconsin Technical College System Foundation. (1994). **Nursing assistant video-based instruction.** [Video] Waunakee, WI.

Yeo, G. & Gallagher-Thompson, D. (Eds.). (2006). **Ethnicity and the dementias.** (2nd ed.). New York, NY: Routledge.

Zgola, J. (1999). **Care that works: a relationship approach to persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

Zgola, J., OTC. (1997). Programming. In **Key elements of dementia care.** Chicago, IL: Alzheimer's Association National Office.



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Contributions to Philosophy and Values Statement

Person-centered ideas:

- Decision-making power is in the hands of the individual or in the hands of those closest to her/him when the individual is unable to make a decision.
- Individuals need to be given choices.
- The individual comes before the task.
- Families and DCWs work together to support individuals with dementia while maximizing their autonomy.
- Dementia care focuses on the individual and on building relationships.
- Dementia care looks at "doing with" the person, not "doing for."
- Dementia care identifies and focuses on the individual's strengths, not deficits.
- Dementia care establishes familiar routines to promote individualized care.
- Each individual's experience of dementia is unique; therefore, care must be unique.

Growth ideas:

- Within each individual lies the potential for growth and the ability to make a difference.
- Promote the growth and development of strengths and abilities for all.
- When you "care" things grow. "Care" does not mean "treat."
- Provide opportunities to give as well as to receive care.

Caring ideas:

- A prime task of dementia care is to maintain personhood – or to know the person – not just meet the person's physical needs.
- Companionship should be integral part of "care."
- The focus on retaining abilities is important in caring for the individual with dementia.
- Friendship is also a key component in caring for the individual with dementia.
- Care should respect diversity.
- Holistic care responds to the individual's spirit, mind, and body. There should be opportunities to give as well as receive care.
- Care must be continuous and lifelong.

Environment and Culture Ideas:

- The focus is on helping individuals in their homes or home-like settings.
- The emphasis is on making the person feel "at home."
- The environment should foster relationships between individuals and DCWs.
- A community-like setting, not an institutional one, is the goal.
- Culture changes are a journey.

- The environment should be one in which interactions and happenings take place naturally.
- The environment should foster variety and spontaneity in daily life.
- The environment should adjust to the comfort needs and abilities of the individual and ensure a sense of community and security.

For trainers and supervisors of direct care workers:

- Each worker can and does make a difference.
- Practice self-examination and reflection, searching for new creativity and opportunities for doing better.
- Empower DCWs to build relationships.
- Offer a learner-centered approach.
- Emphasize a curriculum that develops interpersonal, problem solving, and communication skills in an environment that carefully balances support and accountability.
- Empower DCWs to be forward thinkers—breaking the mold and testing new ideas.
- Promote growth and development in a supportive environment encouraging DCWs to use their full potential.
- Involve DCWs in decision-making around care delivery.
- Actively engaging in the discovery process is core for training workers.
- Provide opportunities for DCWs to develop quality relationships with the individual, which gives work meaning and purpose.
- Promote open communication with other DCWs and professionals.
- Give DCWs the tools they need to effectively work with people with dementia at all stages.
- Set standards of excellence.
- Use informal leadership.
- Celebrate accomplishments.
- Understand individual capabilities.
- Ensure individuals' rights.
- Recognize personal limitations.
- Provide "hands on" training and coaching.
- Show workers techniques for gaining the individual's trust.
- Give staff tools to learn the individual's history.
- Use structured and unstructured activities.

Reviewers

The workgroup appreciates the valuable comments provided by reviewers and carefully considered all feedback. However, the final document may not reflect the recommendations, opinions, or preferences of individual reviewers.

Dale Adler, MA
Jean Barnas, MA
Debbie Conarty
Kathryn Ann Kozlinski, LPN, MEd
Chris Simons, CTRS
Rachel Richards, BA
Portia Ross-Morehead, DCW
Kim Walsh, MS
Shelly Weaverdyck, PhD
Adult Day Programs of the Alzheimer's Association, Greater MI chapter – Southfield
and Southwest Detroit
Complete Compassionate Care home health workers
Seasons Adult Day Services

Feedback Form

Please continue your answers on additional pages if needed.

1. What did you find most helpful in the guide?

2. What suggestions do you have for improving the guide?

3. How long has it been since you first received the guide?
 - Less than one month
 - 1 - 3 months
 - 3 - 6 months
 - 6 - 12 months
 - More than a year

4. Has using the guide led directly or indirectly to any change in how you provide care?
 - no change (skip to item 6)
 - some change
 - a lot of change

5. Please describe what changes you have made as a result, directly or indirectly, of using this guide:

6. Other comments:

Continued...

7. How many years of experience do you have as a direct care worker?

- Less than one year
- 1 - 3 years
- 3 - 5 years
- More than 5 years

8. How many persons with dementia have you cared for?

- Fewer than 3
- 3 - 5
- 5-10
- More than 10

9. In what settings have you worked? (Check all that apply.)

- Assisted living
- Nursing home
- Hospital
- Hospice
- Home Health Care
- Home Help Program
- Other _____

Thank you for your feedback. Please email your forms or comments to lcornelius@mphi.org , fax them to 517.324.7364, or send them to:

Dementia Program
Michigan Public Health Institute
2438 Woodlake Circle, Suite 240
Okemos, MI 48864

