DEMENTIA CARE SERIES

Michigan Department of Community Health THOUGHTS & SUGGESTIONS FOR CARING

 $C_{aring} \, S_{heet} \, \# 14$: Helping with Daily Tasks

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Introduction

There are many suggestions available for how to help a person with dementia perform tasks or activities of daily living, such as bathing, dressing, eating, and using the restroom.

This caring sheet outlines some of the basic intervention concepts under which the various intervention strategies can be organized. With each concept, an assessment question and examples are given as well as a rationale based on brain changes which frequently occur in dementia. Caring sheets #1 and #2 list the various changes in the brain and cognition common in dementia.

The intervention concepts presented are themselves organized into the four factors useful in assessment and intervention planning: Person, Environment, Caregiver interactions, and Task.

The brain damage in dementia sometimes causes a person to have emotional reactions and behaviors that are distressing to the person and to the caregiver. The brain damage also leads to an impaired ability to perform a variety of tasks.

While brain damage is the cause of such changes, many of the triggers which seem to determine whether a behavior or impaired ability emerges at a given time, reside in the environment, interactions with other people, and in the timing and structure of the task.

Interventions which modify the environment, interactions, and task characteristics can contribute to the success of a person's performance of a task and to the reduction of symptomatic behaviors. The success of the interventions often depends upon the extent to which they compensate for the underlying brain damage in dementia.

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As in all aspects of dementia, each person is unique and changes over time and from day to day. Therefore interventions must be adapted to each individual and to each occasion.

ENVIRONMENT

1. **Contrast:** Are there contrasting color intensities (dark against light) to draw attention to areas or items you want the person to notice and use, and no contrasting color intensities to divert attention from areas you want the person to avoid?

Examples: light switch against wall

wall against floor

shower hose against tub or shower towel against wall or towel rod

grab bars against wall toilet against floor plate against table

table against floor against chair

electrical outlets same color intensity as wall

doors to dangerous areas same color intensity and pattern as wall

Why? With normal age related sensory changes and changes in the brain's ability to recognize (perceive) distinctions in the environment, items begin to blur together. A glossy white toilet against a light linoleum floor are difficult to distinguish, as is a white grab bar against a white tub or shower wall. Also, for the same reasons, items may be difficult to locate in space. Because brain changes might cause a person to respond easily to all stimuli, even irrelevant stimuli, it is best to highlight only the appropriate stimuli.

2. Texture: Is there sufficient texture to the walls and floor?

Examples: carpet, rubberized or similarly textured and nonslip floors

cloth hanging on walls drop textured ceilings seat cover on toilet varied texture to foods

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Why? Smooth shiny surfaces and floors cause light and noise to bounce and echo. The room becomes very glaring and bright with light colored shiny surfaces. In a large noisy dining room or in the bathroom when water runs, the noise with echoes can be deafening to a person with a hearing aid or who is hearing impaired. Older people are usually sensitive to glare. Background noise often prevents them from hearing. When a person also has a cognitive impairment, it is very difficult to compensate for this sensory loss by figuring out what someone is saying. Hence a person can become very frightened or annoyed and unable to function well.

3. Lighting: Is there bright, diffuse, and nonglaring light with no shadows or darker areas in the room?

Examples: no confusing shadows, glare, or dark patches on the floor

closet interiors as bright as rest of room

side lighting by mirror rather than only overhead lighting

Why? Side lighting removes the shadows on the face in the mirror. Shadows and glare on the floor are easily misinterpreted as wet spots or indentations because of changes in depth perception with normal aging and with brain changes.

4. Cueing: Is there sufficient information or cueing available to the person in a way that is understandable?

Examples: signs on walls and appliances

name or photo by bedroom door

note or sign by clock saying date and schedule (e.g., time for lunch)

drawings instead of words on signs as appropriate cues placed at heights and places they will be noticed tubs and equipment that look normal and recognizable

marks on the tub to indicate depth of water

Why? A person depends on the environment increasingly as the cognitive impairment becomes more severe. The brain's ability to figure out what to do in the absence of stimuli or when stimuli are unfamiliar is impaired. If a tub or shower doesn't look normal, it can be confusing and the person doesn't know what to do in this room. It can also be very frightening, even if the caregiver tries to explain what it is. The water in the tub may look much deeper than it is. Word signs may help if the person can read and if the person understands what she or he reads. Because of memory loss, however, cues must be repeated frequently to reassure and inform the person.

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5. Patterns: Is the floor plain and clear with no geometric or decorative patterns?

Examples: no alternating block patterns

no light colored or dark colored specks

Why? Geometric or intricate repetitive patterns can make the floor look like it's moving or undulating which can alter the sense of balance in a person with vision and brain changes. A person may be tempted to pick up specks on the floor, thereby increasing the chance of falling. The floor should feel safe with no distracting stimuli.

6. Homey: Does the room feel homey, warm, cozy, comfortable?

Examples: warm bright colors

no unrecognizable objects in the room

nothing in the room that would not normally be there in a home

soft music playing

temperature warm enough

Why? The brain changes prevent the person from remembering the caregiver's reassuring words or may make it difficult to understand words. The person relies on nonverbal environmental indications of safety and supportive comfort for reassurance. Confusing or unfamiliar objects in the room drain the person's energy as she or he tries to make sense of the object. The body's ability to regulate its own body temperature may be erratic or impaired in some way, making the person heavily dependent on the temperature of the environment to stay warm. With normal aging a person usually feels colder than she or he used to, so for a room (particularly the bathroom during a bath or shower) to be warm enough for the person, the caregiver will likely have to be quite hot.

7. **Clutter:** Is unnecessary clutter removed; does the number of items in the environment fit the person's needs and abilities?

Examples: reduced number of decorations and food or hygiene items

some items brought only when they are needed

mirrors covered or removed if necessary

Why? A person's ability to tolerate clutter varies with personality and with the type and amount of brain impairment. It is important to assess the person's ability and to remove clutter as needed. Sometimes a mirror reflects too much light or movement that is blinding or confusing. Sometimes a person can't recognize her or himself and thinks someone else is in the room.

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8. Privacy: Is privacy assured?

Examples: doors can close and lock, depending upon needs and abilities

windows are covered

only necessary people are in the room

Why? Even when a person is very impaired, she or he may still retain a sense of modesty in a bedroom or bathroom or during a meal if she or he senses a reduced ability to eat without being messy. Privacy also reduces distracting stimuli, such as background noise and excessive movement.

CAREGIVER INTERACTIONS

1. Characteristics: Am I as caregiver the best one to help with this task?

Examples: the gender of the caregiver matches the person's preference

the person views the caregiver as someone they trust and like the caregiver likes, loves and is compassionate with the person the caregiver feels comfortable helping the person with this task

Why? The person's ability to recognize faces is often impaired. The person may think a caregiver is someone else (e.g., that a daughter is a mother) because of genetic similarities or because the daughter now looks like the person's mother did some years earlier. The person's ability to recognize passage of time and its consequences is impaired. The person may also have emotional reactions to trauma suffered years ago when the caregiver looks like someone from the past. If a person's behavior such as sexual invitations, triggers discomfort or painful memories for the caregiver from the caregiver's own past, then it may be better if someone else became the caregiver.

2. One at a time: Is there only one caregiver interacting with a person at a time? In the unusual circumstances where it truly requires two caregivers to assist with a task, then is only one caregiver interacting with the person and engaging the person's attention, while the other caregiver silently and out of the person's visual field, does the other tasks?

Examples: one caregiver holds the person's hands and converses the other caregiver washes or hands supplies to the fist caregiver the two caregivers trade roles when the person gets angry at one the two caregivers communicate with each other silently

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Why? Because of brain damage, the person can usually focus on only one person or task at a time. It is very tiring to shift gears from one caregiver to the next and can cause unnecessary fatigue. The person also has difficulty ignoring some stimuli in order to attend to a relevant stimulus. Two caregivers may have to compete for the person's attention and focus.

3. Respect as an adult: Am I as caregiver showing respect for the person nonverbally and verbally, and treating the person as an adult?

Examples: no condescension or demeaning terms of endearment

no descriptions which infantilize ("they are so cute together")

no parental or authoritarian behavior toward person

no scolding or bossing

no children's toys or equipment used

Why? The person with dementia is usually more impaired with words than with emotional recognition and memory. That is, she or he can more easily sense a caregiver's emotional frame of mind through the caregiver's actions and body language than through the caregiver's words. The person usually needs gentle reminders and simple explanations or kind, clear requests, but not scolding or commands. These are likely to be misinterpreted and to elicit emotional distress. A person may not be able to express in words the embarrassment and humiliation resulting from being treated like a child, but the feelings are often there nevertheless. When a person appears childlike through interactions or through the use of toys, other people are more likely to treat the person as a child. The person usually needs not childlike, but simplified task steps, instructions, and equipment.

4. Observation: Do I as caregiver focus on the person and pay close attention to verbal and nonverbal feedback from the person?

Examples: talk only when facing the person with eye contact

give person time to absorb and respond

watch person's entire body for responses and emotional status respond to responses by modifying own behavior or environment

Why? Because a person frequently cannot put feelings into words or even recognize feelings, the caregiver must watch for signs of confusion or distress in nonverbal responses, such as a clenched fist, tightening of the lips, the frown forming. By observing the signs, the caregiver can slow down, or explain again, or reassure or in some way modify the situation to reduce the person's distress or anxiety. By responding to the distress when it begins, the caregiver will likely avoid a more major distress later.

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5. Prevention vs. Response: Am I as the caregiver nipping the person's distress or confusion in the bud, rather than letting it escalate to more challenging levels?

Examples: apologizing or reassuring immediately

watching for feedback and responding immediately coaxing and encouraging in response to subtle hesitations

Why? The rationale is similar to that noted in #4. An ounce of prevention is truly worth a pound of cure. It allows the caregiver to focus on enhancing the person's pleasure rather than simply trying to turn anger into passivity.

6. **Organization:** Am I as caregiver organizing my time well? Do I do most of the task preparation out of sight of the person, so that when I am with the person, I can focus on the person and not so much on the task?

Examples: moving quickly when out of sight, but more leisurely in sight collecting the towels, clothing, soap, etc. before the person sees me warming the bathroom and running the water before speaking have the clothes selected and laid out in order ahead of time preparing food items so each item is warm as person is ready for it

Why? Because the person is slow to process information and frequently gets it mixed up when there are competing stimuli, the caregiver should move around as little as possible and try to focus entirely on the person to enable the person to complete the task without getting overly fatigued and frustrated. Good organization also allows the caregiver to appear calm, relaxed, and reassuring to the person, while getting the task done in a timely fashion. The emotional tenor of the situation depends heavily upon the caregiver.

7. Body Language: Is my body telling the person what I want it to say?

Examples: appropriate body position

sitting beside person or kneeling

staying within the visual field the person attends to

body matches face, eyes, and words getting in the shower with the person

eating or brushing own teeth at the same time the person is

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Why? As previously mentioned, the person with dementia usually responds to nonverbal cues more easily than verbal. Also, the person may have a part of the visual field that the eye sees but the brain does not pay attention to. It is as though the person doesn't see objects in that space. Some people clearly respond more easily to objects on one side of them versus the other or in front of them versus off to the side. If our words sound cheerful, but our smile looks strained and our body is tense, the person may likely respond to the tension we communicate. If we are using a handheld shower nozzle, then we won't get wet in the shower.

8. Explanation and Reassurance: Does the person need more explanations, or repetitions of explanations, or more reassurance?

Examples: requests or instructions repeated as often as needed explanations are short, simple, and clear explanations occur when noise is reduced caregiver's voice is low pitched and slow questions answered as if it were the first time they were asked person oriented to how much time has passed and the time of day the person is told before being touched the person's body part is touched and rubbed before being moved the person is told when the task is done

Why? The person's memory impairment may cause her or him to forget. It may take several hearings before the instruction or explanation makes sense, since processing information is slowed down in dementia. The person may not have heard because of the background noise. Lowering the pitch rather than raising the volume of the caregiver's voice may be more effective, since it is the higher pitched sounds that are lost in normal age-related hearing impairment. Due to slowed cognitive processes, the person needs time to absorb and respond. Either due to memory loss or an inability to recognize how much time has passed, the person may need to ask questions repeatedly. Sometimes a note the person can refer to helps. Usually a person with dementia has trouble seeing the whole picture, including when a task is completed, and therefore, may need to be told. The person may be inwardly startled and resistant when a part of her or his body is moved without warning. Verbal warning may not be enough. Often the caregiver needs to rub and touch along the body part (e.g., arm or leg) toward the joint before the person is ready to help or to allow the body part or joint to be moved.

9. Distraction: Is distraction or diversion used rather than shame or instructions to stop a behavior to induce a person to change behavior? **Examples:** singing during the task, off and on or continuously

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conversation about visits with family members or friends no comments like "What would your mother say if she heard you?" encouraging the person to hold one item while you use another asking for opinions rather than information during conversations

Why? Because a person finds it difficult to do more than one thing at a time and to ignore powerful stimuli, it is often helpful to hand the person a shaver (turned on) when you are shaving his face with another shaver, or a washcloth, toothbrush, or hairbrush, when you are using a similar item. It also may feel to the person as though she or he is participating in the task whether or not she or he is. When a person is singing or conversing, she or he may not notice the shower as much. Singing familiar songs can also be reassuring. Because the brain damage makes it difficult for the person to produce information on command, it is easier for them and often more engaging for them to discuss their opinions instead. Again, because the person cannot often do more than one task at a time, feeling the shame of a mistake and changing behavior cannot be done at the same time.

10. Approach: Is my approach helping the person to feel positive about my request or invitation to do the task?

Examples: setting an upbeat relaxed emotional tone

conversing with the person for a while before mentioning the task saying the first step (a walk) instead of the whole picture (a bath) using a friendly conspiratorial tone; one woman to another suggesting refreshment or fun enticement after the task gently joking and cajoling

rhythmically singing or marching to the bathroom or bedroom

Why? Because the person becomes increasingly dependent upon the environment as her or his ability to analyze and imagine options becomes increasingly impaired, she or he is more dependent upon the caregiver to feel good with an upbeat emotional tone. The caregiver does this by being friendly, smiling, conversing in a relaxed comfortable way and being warm and affectionate. Sometimes talking in a warm conspiratorial tone (one woman to another) about slipping into the ladies room to freshen up and help each other with potentially embarrassing tasks works well. Many times a person feels overwhelmed at the thought of trying to navigate through all the

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steps of a shower, bath, dressing, or meal. She or he responds more willingly to an invitation to do the first step, such as a walk which ends up at the bathroom if the bath hasn't been mentioned. As the dementia progresses just walking to specific destinations on command can be a challenge. A strong powerful rhythm often helps the person move their body.

TASK

1. **Task Goals:** What does the person want and need from this task?

What does the caregiver want and need from this task?

Examples: the person wants to feel relaxed and pampered

the caregiver wants to get the job done quickly

person eats ice cream during bath

caregiver washes only those parts that need to be cleaned

person eats or dresses while walking

Why? As caregivers we tend to think of a meal as a time to get nourishment or a bath as a method to get clean. We also tend to think of a bath as the only way to get clean, and that a person needs to be cleaned at least twice a week. The person may have a different opinion and may have done things differently in the past. (This current older generation often did not bathe as often as the younger generation.) The person may need the bath to relax or to soothe anxieties. Making the bath more appealing may encourage the person to like the bath. As the person's skin dries out with advancing age, it may be better to reduce the skin's contact with harsh soaps.

2. Task Steps: Are the task steps too many, too complex or too unfamiliar?

Examples: task broken down into steps

caregiver performs most difficult steps adaptation of pace of task to person's needs

bathing done in stages; different body parts at different times

sponge baths at sink or in bed

eat first and then drink

Why? The ability to understand a whole task and to recognize the steps that make up the task resides in a part of the brain that is severely impaired in mid stage and late stage dementia. People with dementia are therefore easily overwhelmed resulting in withdrawal, resistance, anxiety, or anger. The bathing or showering task may be the most emotionally challenging and most complex task a person must do, since it includes removing all one's clothes (and feeling the vulnerability which comes with nudity) and

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dressing, which uses all one's body parts for both moving (motor) and feeling (sensory), as well as higher cognitive functions. Breaking the task into simpler steps over time can be very effective. Using sponge and bed baths is a good substitute with fewer tasks and less vulnerability. Because a person's speed of processing is slowed, the caregiver must be prepared to vary the pace according to the person's responses.

3. Consistency: Is the task done the same way, same time, and with the same people each time it is performed?

Examples: the same caregiver always assists with the task

the task is done on the same day and time the routines become habits with few surprises

frequency adapted to person's preferences and needs

Why? The ability of the brain to adapt to change or new ways of doing things is very impaired. The person with dementia can usually do a task better if she or he doesn't think about it. Change requires a person to focus on the task and think about each step. The frequency and schedule for the bath or shower usually is most effective when it conforms to the person's habitual time in the past. This too must be flexible, however, to accommodate the person's fluctuating needs.

4. Modification of steps: Are the task steps modified to fit the person's needs or preferences?

Examples: bath schedule fits the person's past habits

a person removes clothes after stepping into the wet shower shower nozzle is sprayed through a towel draped over the person

only one part of a person's body is exposed at a time

a towel remains draped over the person throughout the shower

feet are washed first and hair last

towels on floor to prevent slipping and cold feet

food served throughout the day rather than only at meals or snacks

Why? A person with dementia develops unpredictable fears and misinterpretations of the environment as the dementia progresses. Adapting the task to the person's changes allows her/him to continue the task. A person may not want to take the clothes off because she or he is frightened to be naked, or doesn't want to go through the challenging steps of taking them off. In extreme cases, and if the person doesn't get upset about the clothes being wet, stepping into the shower fully clothed alerts the person it's time to take the clothes off. Sometimes the brain changes causes a person to feel a soft spray of water as pellets on their skin, which is painful or at least very

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uncomfortable and frightening. A towel over the nozzle or draped over the body can reduce the force of the spray against the skin. To prevent a person from feeling so cold and to respect modesty, it is important to uncover only one part of the body at a time and to keep a towel draped over the person throughout the shower. Washing the feet first is sometimes less threatening to the person. Sometimes the brain changes prevent a person from recognizing body parts farthest away from the middle of her body or from her head as part of her own body. Washing the feet first allows the recognition of her own body as being washed to dawn on her gradually.

5. Modification of objects: Are the task objects modified to fit the person's needs or preferences?

Examples: clothes are adapted with increased impairment

women's pants are replaced with skirts, or over heads with buttons

the shower nozzle is covered with a wash cloth or sponge the water temperature adjusted for person's changing needs the water pressure adjusted for person's changing needs

rolling chair to sit on in shower or bath only one food item at a time during meals more finger foods or soft foods offered

Why? The dementia progresses (and the person's ability to think and perform tasks becomes increasingly impaired) because the brain damage is becoming increasingly severe. Unless the unfamiliarity and change are too challenging, a person can more easily wear a skirt than pants (particularly if incontinence occurs). As the person's body becomes more impaired in its ability to adjust to changing temperatures and to experience water pressure on the skin consistently, the person's tolerance for showers will also change. The caregiver can help keep the bathing experience pleasurable or at least tolerable by adapting to the person's changing sensations. As the person becomes less able to walk or move, equipment such as a rolling shower chair or bath chair can make a big difference to both the resident and the caregiver. The person's ability to eat foods other than finger foods frequently declines. Metabolic changes as well as cognitive changes often cause a person to feel constantly hungry, yet unable to eat large quantities at a time.

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Conclusion

There are many intervention strategies that can be used to help a person with dementia perform a task with as much ease and satisfaction as possible. It is important to choose intervention strategies effectively and with sensitivity to the person's individual preferences, strengths, and needs at any given time. To the extent a caregiver chooses interventions successfully, a person with dementia can live a more meaningful and pleasurable life.

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