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UNDERSTANDING DEMENTIA

Many people are afraid to discuss changes they may be noticing in either their own or someone else's behavior. There can be confusion about whether such changes are due to normal aging or due to the onset of a disease. This document describes common symptoms of dementia; the evaluation that determines the cause and diagnosis; and explains different types of dementia.

What does dementia mean?

Dementia refers to a gradual decline in memory and other cognitive functions. It is a broad term describing a widespread problem in brain function. The symptoms of dementia interfere with an individual's daily activities. These symptoms can include, but are not limited to:

- ❖ Forgetting events, names, places.
- ❖ Repeating questions.
- ❖ Difficulty finding words or putting thoughts in conversation.
- ❖ Problems managing money or balancing a checkbook.
- ❖ Getting lost in familiar places.
- ❖ Trouble doing work or routine tasks.
- ❖ Personality changes.

There are many causes of dementia, Alzheimer's disease being the most common. It is important to look for the cause of dementia, so a diagnosis can be made and appropriate treatment started.

Is dementia a normal part of aging?

Contrary to popular thinking, dementia is not a normal part of aging. Most people over age 60 never show signs of cognitive decline. Although the likelihood of dementia increases with age, dementia affects only a minority of older people. It is true that as a person gets older, it takes longer to learn something new. However, once an older person has learned something new, it should be remembered as well as when the person was young. When there is a pattern of failing memory, it is considered abnormal and should be evaluated as a medical problem.

How is a diagnosis made?

Determining the cause of dementia requires a thorough evaluation. The evaluation may include blood tests and a brain scan. If some tests have been done previously, it may not be necessary to repeat them. The various components of a comprehensive evaluation are described below.

The history:

Getting a complete medical history is the first step in the evaluation. This entails an interview with the individual and their spouse, relatives or close friends. Interview questions are designed to determine the onset of any cognitive or behavioral changes. It is important to know if there is a history of head injury, loss of consciousness, seizure, stroke, diabetes, thyroid disease or alcoholism. In addition, information about the person's education, work, and family history will be collected.

Neurological examination:

The purpose of a thorough neurological examination is to look for any physical findings that may account for cognitive and/or behavioral changes. Illnesses such as stroke, tumor, or Parkinson's disease may cause brain changes that mimic Alzheimer's disease. Brain functions that are typically tested include: memory, language, perception, orientation and motor skills.

Laboratory tests:

At the discretion of the clinician, certain laboratory tests and brain scans may be indicated. These may include blood work, scans of the brain, such as a CT, or MRI.

THE STAGES OF ALZHEIMER'S DISEASE

Families often ask which stage of Alzheimer's disease their relative is in. Although we can identify and describe stages of the disease, it is important to remember that the disease develops differently in each person. Some people may appear to change very little over a period of many years, while others show a rapid decline within just a few years. The reasons for these differences are not yet understood.

Although each person progresses at a different rate, a description of general patterns of dementia may help determine suitable activities and resources.

Early stage/mild impairment

- ❖ Impairment of recent memory is usually the hallmark of the disease in this stage. People with early-stage dementia often write down reminders as a means of maintaining their independence as much as possible.
- ❖ The person may have difficulty performing calculations, integrating a lot of information, following multiple steps or directions and making complex decisions.
- ❖ The person may be unable to perform certain household tasks or job responsibilities. Decision-making, handling multiple duties and operating machinery may be too difficult to do well or safely.
- ❖ Problems develop in handling finances such as preparation of taxes, payment of bills or maintaining a checkbook.
- ❖ Although driving skills may become impaired, each case of driving safety needs to be assessed on an individual basis.
- ❖ The person with dementia may feel more comfortable in smaller groups and with well-known family and friends in familiar surroundings. The individual may be aware of their impaired memory and fearful of embarrassing themselves in social situations.

Although dementia imposes limitations, the person with early-stage symptoms is still able to enjoy many normal activities. Family members should emphasize the person's remaining abilities instead of focusing on the impairments.

Middle stage/moderate impairment

- ❖ The person often repeats questions.
- ❖ Difficulty with written and spoken language becomes more prominent. For example, trouble finding the right word in conversation may increase.
- ❖ Getting lost or disoriented in familiar surroundings may occur.

- ❖ Understanding concepts such as time and other abstractions may become more difficult.
- ❖ The person becomes unable to manage personal grooming and hygiene. At this point, you may need to take a more active role in assisting the individual to initiate and follow through on certain tasks such as bathing and brushing teeth.
- ❖ Losing things or hiding things may become problematic.
- ❖ In this stage, frustration or agitation may arise around certain situations. For example, when the person misplaces items such as keys, others may be blamed for "taking" the objects. Poor memory and misperceptions about the environment may lead to agitated behavior.

Late stage/severe impairment

- ❖ This stage is characterized by the inability to remember even the most basic things. Short-term and long-term memory are profoundly impaired.
- ❖ Language may be reduced to a few basic words.
- ❖ Incontinence (first of urine and then of bowel) usually occurs.
- ❖ The person ultimately becomes totally dependent and must be assisted with all tasks such as bathing, dressing and eating.
- ❖ Communication with the person must be carried out in very simple terms using short sentences, commands and gestures.
- ❖ Mobility may become unsteady or may be lost altogether.

Even in this late stage, a person with dementia is able to respond to emotions of happiness, anger and love. Although the words you use to express these emotions may not always be understood, you can communicate how you feel by nonverbal means such as touch and gestures.

BRIDGING THE COMMUNICATION GAP

Dementia affects communication in many complex ways. Understanding these changes will help keep alive your relationship with the person with dementia. Learning new ways to communicate should also make your role more meaningful and less frustrating. You may find that the person's capacity to communicate fluctuates from day to day or with different people. The person's ability to communicate is affected by the following:

- ❖ Difficulty finding the right word when speaking and difficulty understanding the meaning of written and spoken words.
- ❖ Having a limited attention span, which makes it difficult to follow lengthy conversations or multiple step instructions.
- ❖ Losing train of thought when listening or talking.
- ❖ Difficulty remembering the steps in common activities, such as cooking a meal, paying bills or doing laundry.
- ❖ Difficulty filtering out background distractions that seem to compete for attention (radio, television, telephone calls, the conversations of others in the room).
- ❖ Getting frustrated if communication isn't working.
- ❖ Being hypersensitive to nonverbal aspects of communication such as gestures, touch,

tone and volume of voice.

- ❖ Reverting back to a native language if English is a second language.

Making communication easier

No suggestions for improving communication work all the time with every person. Experiment with different methods of communication before settling on those that work best. Your methods will change as the disease progresses over time. Don't modify your way of communicating with the person unless you find that they can no longer understand you.

It's easy to slip into the habit of only communicating about tasks and the issues of day-to-day care. People with dementia, like all of us, have basic human needs: to feel safe, cared for and valued. Encourage a dialogue as long as possible. This helps the person with dementia maintain self-esteem long into the illness. Keep these suggestions in mind:

- ❖ Establish eye contact to get the person's attention first, before proceeding with what you have to say.
- ❖ Offer simple, step-by-step instructions.
- ❖ Ask questions that require a yes/no answer.
- ❖ Repeat instructions if necessary and allow more time for a response.
- ❖ If words alone don't convey what you want, try a different approach: show the person and use touch to gently guide them.
- ❖ Try using different words to convey what you want. Perhaps the appropriate word in the person's native language would work.
- ❖ If you find yourself becoming too frustrated, drop the effort as calmly as you can and return to it when you're in a better frame of mind.
- ❖ If verbal communication fails, try distracting the person. Instead, offer a pleasant activity like a snack or a ride around the neighborhood.
- ❖ Ignore angry outbursts if you can't think of a positive response.
- ❖ Be aware of your whole approach: tone and volume of voice, facial expression and body posture.
- ❖ Try not to correct or dispute "errors" in memory. Avoid saying "Don't you remember?" or "I told you..."
- ❖ Begin your conversation socially. Winning the person's trust first can often make a task much simpler.
- ❖ Your manner should be warm, affectionate and matter-of-fact.
- ❖ Allow sufficient time for a familiar activity and try not to rush it.
- ❖ Avoid criticizing mistakes. Instead say, "Let's try this way."
- ❖ Support each effort or attempt, even if the results aren't completely satisfactory. Say, "Thanks for helping."
- ❖ Be aware of how the person responds to you. These clues may give you important feedback that will help you detect a problem before it develops and allow you to adapt your communication.
- ❖ Be open to the person's comments and concerns even if these are difficult to hear.
- ❖ Sometimes "problematic behaviors" are a way of keeping control of daily life or expressing frustration. Let the person make some decisions and stay involved.

The book, *Understanding Difficult Behaviors*, gives good advice about how to communicate with persons with dementia. The authors break their chapter on communication into seven parts: focusing on tone, topics of discussion, complexity of conversation and tasks. Below is their list of “things to do” with persons with dementia:

- ❖ Don't argue with the person.
- ❖ Don't order the person around.
- ❖ Don't tell the person what he or she can't do. State directions positively instead of negatively.
- ❖ Don't be condescending.
- ❖ Don't ask a lot of direct questions that rely on a good memory.
- ❖ Don't talk about the person in front of them.

A man with Alzheimer's disease, quoted in the book *The Loss of Self*, seems to express the feelings of many people with dementia:

“No theory of medicine can explain what is happening to me. Every few months I sense that another piece of me is missing. I can only think half thoughts now. Someday I may wake up and not think at all . . . not know who I am. Most people expect to die someday, but whoever expected to lose their self first? I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free until my self no longer exists.”

HELPING THE PERSON WHO IS AWARE OF MEMORY LOSS

It was once commonly thought that people with Alzheimer's disease were unaware of their memory loss. We now know that some people with dementia show a great awareness of their disease, while others are completely unaware. There is little research to help us understand which individuals are aware of their symptoms and how we can help them cope with this awareness.

Some people may deny anything is wrong with their memory. Such denial may be their way of covering up or compensating for their cognitive deficits. On the other hand, some people simply forget that their memory is impaired. These people do not remember that they do not remember! Such a notion may be hard to grasp for those of us who take memory for granted. Our own reluctance to approach people who have dementia and inquire about their feelings may be a roadblock to their acceptance of memory loss. If the person needs to talk about the changes they are noticing, take time to listen. Be as honest and sensitive as you can. Following are other ways you can help:

- ❖ Many people with dementia want to share what is happening to them, particularly when they notice problems doing once-familiar things, such as balancing the checkbook or preparing a meal. Take time to listen.
- ❖ Because of difficulties with word-finding, the person may need your patience as they try to put feelings into words. Help them find words, but don't force a conversation.
- ❖ Remember that as the person loses verbal language skills, they will rely on certain

behaviors to communicate thoughts and feelings. It may be helpful to say out loud what the person may be experiencing. Ask "Are you frustrated right now?"

- ❖ Find out about support groups in your area for people diagnosed with Alzheimer's disease. The Alzheimer's Association has developed such specialized groups through its local chapters.
- ❖ Ask your local Alzheimer's Association chapter or a health care professional about books and articles written by people with dementia. Many videotapes also describe Alzheimer's disease from the perspective of someone with the disease.
- ❖ Your efforts to acknowledge and support the emotional needs of the person with dementia can go a long way towards maintaining their quality of life.

CREATING A SAFE HOME

The environments in which we live or our everyday surroundings are made up of a rich variety of things we see, hear, smell, taste and touch. Though many of us may not pay much attention to our surroundings, we can usually identify things that we find uncomfortable or distressing and take action to correct any situations that cause us discomfort. To block out a noisy street, we can shut the window. If it's chilly, we might put on a sweater. But for the person with dementia, these solutions are not so simple.

Dementia changes a person's ability to understand, interpret and respond to what is happening in the environment. The person may easily be confused by what goes on around them. As a caregiver, one of your most important responsibilities is to monitor the home environment. Start by paying careful attention to how the person responds to the sounds and sights of their surroundings.

Controlling noise and activity

Noise and activity can confuse and trouble the person with dementia. They may become overwhelmed by noise or not be able to track where sounds are coming from and think what's happening on television is actually taking place in the room. Similarly, when they hear someone talking loudly, they may think they are being scolded. The individual may feel threatened and become tearful or aggressive. Loud noises such as from a hammer or blender can cause stress and confusion. Even certain music may be disturbing to the person. Try as much as possible to limit confusing noise in the environment. Shut off the radio and television when they aren't in use. If noisy activities must take place in the home, see that the person is away during that time. When entertaining guests, limit the numbers of people coming and going at one time to keep commotion to a minimum.

Handling problems with visual stimuli

Just as noises can overwhelm and confuse the person, so can visual stimuli. Patterns on drapes, floor coverings or clothing may look three-dimensional to the person with dementia. They may try to pick up the "pieces" or trip on a patterned floor. Seeing one's face in a mirror might confuse them and they might also mistake their image for that of another person. Rearranged furniture in a room or the addition of holiday decorations can also be troubling. The key is to keep the environment consistent. Minimize clutter in the person's surroundings. This will help them get around more safely. If mirrors are troublesome, cover or remove them. To prevent slips or falls, remove area rugs or tack them down. If you're installing floor covering,

choose a simple pattern not a busy one. Night-lights in the hallways will help the person see at night. An excellent book that is full of practical advice about home safety is *Homes That Help: Advice From Caregivers for Creating a Supportive Home*.

KEEPING ACTIVE

Persons with dementia need to be active and have meaningful things to do. "Activity" refers to the doing or interaction between the individual and their environment, defined in its broadest terms to include physical, social, and cultural environments. Activities are the tasks that give purpose, meaning, and definition to one's daily life. Working in a kitchen or a yard, reading a book, listening to music, singing a song, watching television, or visiting with a neighbor are activities. Activities also include things related to taking care of oneself, such as bathing, grooming, and eating. Most of these activities are tasks that a person does routinely throughout life and can be done without much thought. Such activities are integral parts one one's day and contribute to feelings of control and mastery.

A person with dementia usually has difficulty deciding what to do each day. The day may appear like a vast space of unstructured time. This may evoke feelings of worry and fear. The apathy and tendency to withdraw from others sometimes displayed by persons with dementia may be related to difficulty with planning and initiating activities and tasks. The person with dementia is not being lazy or unproductive, but may need someone to give structure and direction to their day. Jitka Zgola, an occupational therapist specializing in Alzheimer's disease writes:

"We do things to define ourselves as individuals, to exert control over our environment, and to develop and secure meaningful relationships with others. Alzheimer's disease gradually erodes a person's ability to engage in many of the activities that fulfill these basic psychosocial needs. It then becomes the responsibility of the [caregiver] to offer the [person] alternatives that enable him or her to continue with meaningful activities."

Activity ideas

There are general types of activities that persons need to be involved in each day. A good variety of activities can be both stimulating for the person with dementia and can be a diversion or help to the caregiver. A balance between household and leisure activities will include social, physical, cognitive and spiritual activities.

Household activities:

Washing dishes, sorting mail, clipping coupons, sorting socks, folding laundry, sweeping the floor, polishing shoes, raking leaves, weeding in the garden, watering plants, rolling dough, snapping green beans, sorting recycling materials, sorting cards, are fairly simple work activities that can be done independently or with some assistance. When the person with dementia engages in these activities, it is important to dignify the work and be thankful for their assistance.

Music activities:

Music has universal appeal. Listening to a specific song may or may not be familiar to the individual, but it may be enjoyable because of its rhythmic quality and its ability to trigger

emotions and memories. Musical activities might include playing records or tapes, singing old familiar songs, dancing, reminiscing about the music and past events, or playing musical games like "Name that Tune." Listening to a favorite musical or opera and discussing the story and the composers can be enjoyed alone or together. Consider attending a concert or an afternoon matinee of a musical production. Such activities might also be useful for a visitor unsure about what to do or talk about during a visit.

Pets:

There is something magical about the presence of a dog, a cat, or a bird which seems to bring people to life. Pets can offer opportunities for a person with dementia to still enjoy some responsibilities. Being with an animal also increases socialization, decreases anxiety, and provides a nice diversion from the frustration of memory loss. Activities that incorporate the use of such animals can be basic pet care like grooming, feeding, and exercise.

Gardening:

Staying connected to nature is an important way to be productive and care for other living things. Working with plants indoors or in an outdoor garden can spur memories of past summer days and enjoyable times spent outside. Planting herbs, flowers, and vegetables can help support remaining talents and provide an ongoing project. Watering the plants each day, discussing their progress, and reminiscing about past gardening experiences make the days fuller and more meaningful.

Children:

Staying in touch with children of all ages keeps a bridge between the generations and can often stimulate conversation and memories. Both children and older adults increase their self-esteem, develop mutual respect, and form deeper bonds if they can enjoy their time together. Consider playing simple board games or reading stories or books together. Consider visiting relatives with small children and having young mothers visit with their babies. Walks in the park and school yards provide exercise and trigger conversations about children. Consider attending school or church programs involving young people.

Outings:

Early in the disease, outings that were fun in the past should be continued. Consider such outings even as the disease progresses and modify them as needed. Trips can include walks at the zoo, botanical gardens, forest preserves or shopping malls. A swimming pool during a slow time offers great sensory stimulation. You may want to consider using a business card for such public outings that states, "My companion has Alzheimer's disease. Thanks for your consideration." This information can be shared with store clerks and restaurant staff and can make outings more comfortable for all involved. Outings should be carefully planned based on length of the activity, time of day, and destination that allows for maximum success.

Physical Fitness

Staying physically active is a key component of well-being. Not only does exercise provide physical benefits but it can also improve one's mood. A daily walking routine is one of the simplest and most beneficial physical activities. If the person with dementia walks alone, then an ongoing assessment of safety is crucial. It is a challenge to allow the person with dementia

to be independent while at the same time planning for safety. Consider making "Sit and Be Fit" a regular part of a daily routine. This is a TV program that emphasizes range of motion and low-impact aerobic exercise. There are also exercise videos specifically tailored to the exercise requirements of older adults. As in any exercise program, a standard routine should be followed to ensure proper warm-up and cool-down. Exercise should always be followed by a drink of water or juice to ensure proper hydration.

Adapting Activities

All activities can be designed to meet the abilities and needs of the person with dementia. Whether the person is participating fully or is a passive observer, each activity can be adjusted to meet one's specific needs. The idea of "grading" an activity to suit one's abilities at different stages of dementia is suggested by Zgola in the book, *Key Elements of Dementia Care*. An example of modifying or "grading" an activity such as baking cookies can be seen at several levels:

1. Independent-organizer-doer (e.g., decides on ingredients, shops, bakes).
2. Independent-doer (e.g., makes cookies, once the recipe and ingredients are prepared).
3. Doer-of-a-specific-task (e.g., measures, mixes and pours, depending on ability).
4. Doer-of-a-modified-task (e.g., does a specific step with help or supervision).
5. Observer-monitor (e.g., listens for the oven timer to go off).
6. Observer-advisor (e.g., tells of own experience).
7. Observer-critic (e.g., tastes cookies).
8. Observer (e.g., watches or listens).

Regardless of the activities that are chosen to fill one's day, a caregiver must take the lead and choose things that are most enjoyable for all concerned. Whether an activity can be done alone by someone with dementia or must be carried out with others, the main point is to maximize opportunities for success and enjoyment.

ENSURING PERSONAL HYGIENE

Oral Hygiene

Good oral hygiene is essential for the person with dementia. When regularly practiced, it prevents dental problems and promotes good nutrition. The following tips may be helpful:

- ❖ You may need to demonstrate the brushing motion for cleaning teeth or dentures, step by step. You may want to brush your teeth at the same time the person is brushing theirs.
- ❖ Supervise denture cleaning and rinse their mouth after each meal if dentures are worn.
- ❖ If you must brush the person's teeth, try a long-handled or angled toothbrush, or one that is electric.

Dressing

A person with dementia often takes more time to dress than in the past. It can be difficult for the person to organize things and make decisions. The person may inappropriately layer

clothes or select the wrong clothing for the season. They may wear clashing colors or forget to put on some item of clothing. Allow the person to dress on their own for as long as possible:

- ❖ Lay clothes out in the order a person should put them on such as underclothes first and then a skirt and sweater.
- ❖ If necessary, hand the person each item of clothing or give step-by-step instructions as needed.
- ❖ Eliminate a large selection of clothes. Keep only seasonal clothes in the closet or dresser and reduce the number of clothing choices.
- ❖ You may want to keep the closet locked and put out one outfit at a time.
- ❖ A person may try to wear the same clothing every day. If so, buy three or four sets of the same clothes and rotate them.
- ❖ Clothing should be loose-fitting and comfortable. Women should avoid girdles, control-top pantyhose, knee-high nylons, garters, high heels, constricting socks and binding bras. Short cotton socks and loose cotton underwear are best.
- ❖ If shoelaces, zippers, buttons and buckles become difficult to manage, try Velcro tape or large zipper pulls for clothing; slip-on shoes that won't slide off or sports shoes; sneakers with Velcro closures and pants with elastic waistbands.

Personal Grooming

Grooming is another important daily activity that should be encouraged for as long as possible. Encourage a woman to wear makeup if she has always worn it. Stick to powder and lipstick only and avoid eye makeup. Encourage a man to shave and help him as needed. Use an electric razor to ensure safety. It's a good idea to continue taking the person to the barber or beauty shop or it may be possible to arrange for the barber or beautician to come to your home. Always keep the person's nails clean and trimmed.

PROMOTING MOBILITY AND EXERCISE

Problems with mobility may occur in the middle to late stages of Alzheimer's disease. People with dementia who are able to walk and move independently tend to maintain a positive outlook and a good quality of life. As control of their life decreases because of the disease, their ability to walk encourages self-confidence. The body needs to move to maintain use of muscles and joints and promote good cardiovascular functioning, weight control, healthy sleep habits and healthy skin. Getting outside every day for a walk should be part of the daily routine. An exercise routine is also encouraged.

The person with Alzheimer's disease may have some problems that limit their mobility and ability to exercise. These include poor endurance, poor coordination, sore feet, an acute illness and confinement to bed. You can encourage mobility by suggesting simple activities around the home such as sweeping and dusting. Try to make the exercise fun by counting repetitions. Have the person wear a radio with earphones to prevent them from being distracted by noises in the room. Suggest the person use a stationary bike to exercise. Balls or balloons can be used for stretching. Be sure the person is safe when they exercise.

Dealing with immobility

If the person cannot move on their own, you can move their body joints with “range of motion” exercises. Move each joint six to eight times. A physical therapist, nurse or occupational therapist should demonstrate this method for you. If these exercises are not done correctly, joints can be damaged. Helping the immobile person to move is very important because it slows the breakdown of skin and contracture of arms, hands and legs.

Here, too, are suggestions to help the bedridden person be more comfortable:

- ❖ To reduce pressure sores, use specialized seat cushions and bed mattresses.
- ❖ Make sure to reposition the person at least every two hours.
- ❖ When the person is seated, give them a lap-board to rest the arms and help support the upper body.
- ❖ A wedge-shaped cushion for the chair that is high in the front and slants to the back of the chair will help the person sit up straight and prevent them from sliding out of the chair.

When the problem is too much mobility

Sometimes a person with dementia walks or paces for hours. Pacing may actually help to ease tension. However, if the person is too active, they may be losing weight and will need to be closely monitored. Make sure the person has sturdy, comfortable walking shoes. Frequent snacks or meals served “on the move” may reduce the possibility of excessive weight loss. Although it should only be implemented as a last resort, a restraining device may have to be used if the person is unsafe to oneself or others. A restraint can be a vest-like garment that is tied to a chair. Such equipment can be purchased at medical supply stores. Ask a health care professional to demonstrate how to use the restraints to ensure they are used safely and correctly; misuse may result in serious injury.

Body mechanics

You must always be aware of your own strength when assisting the person. An injured back, for example, will greatly limit your ability to provide care. To avoid injury when lifting someone, try to use your body wisely. Practice “body mechanics,” described below:

- ❖ Hold person close to your body
- ❖ Bend at knees
- ❖ Place feet apart
- ❖ When lifting, bend at the knees and then straighten your thigh muscles; keep your back straight and do not bend at the waist.
- ❖ Hold the person to be lifted as close to you as possible to avoid reaching away from your body.
- ❖ Keep a wide base of support by placing one foot in front of the other or spacing your feet comfortably apart.
- ❖ Use little steps to move the person from one seat to another; do not twist your body.
- ❖ A physical therapist, nurse or occupational therapist can demonstrate these techniques for you. Ask your physician for a referral to one of these professionals.

DEALING WITH INCONTINENCE

Loss of bowel and bladder control or “incontinence” may occur as Alzheimer’s disease progresses into the late stage. Bowel incontinence is a separate problem from bladder incontinence, and a less common one. One can occur without the other. Whenever incontinence occurs, the person may either be unaware of the problem or, at the other extreme, very upset by it.

Bladder incontinence

Bladder or urine incontinence may occur in a number of ways: leaking or dribbling of urine, emptying of the bladder at once, soiled undergarments or bed linens. In any case, if urine incontinence is a problem, a physician should be consulted. There may be a treatable cause of the incontinence such as a urinary tract infection, enlarged prostate gland, dehydration, uncontrolled diabetes, and use of water pills or excessive amounts of caffeine. The physician will want to know several things about the incontinence, such as:

- ❖ Does the person leak urine when they laugh, cough or lift something?
- ❖ Does the person urinate frequently and can they get to the bathroom on time?
- ❖ Are they urinating in improper places?
- ❖ Is the person taking diuretics, antihistamines, antidepressants or sedatives?
- ❖ Is this a regular or occasional problem?

First of all, you may need to remind the person to go to the toilet every two to three hours in an effort to minimize or prevent incontinence. It is important to keep the person’s clothing comfortable, and easy to remove. Jogging suits, for example, are simple to put on and take off. Keeping a diary of the person’s toilet and fluid intake habits may help manage the incontinence. Does the person urinate first thing in the morning or right after drinking caffeinated fluids? Use this information to develop a schedule.

Make sure the person drinks at least six 8-ounce glasses of fluid each day. Don’t greatly restrict fluids unless a fluid restricted diet has been recommended. If incontinence occurs at night, you may want to limit fluids after 6 p.m. or 7 p.m. Before bedtime, fresh fruit rather than fluids can quench the thirst.

If the person is confused, using the bathroom will be a challenge. There are ways you can help minimize the confusion, such as marking the bathroom door with a colorful sign that reads, “TOILET.” The bathroom should be safe and comfortable; the person may get agitated if the lighting is too bright, or the temperature is too warm or too cold. The toilet seat should be stable and at a good height. Raised toilet seats are available at medical supply stores. Public restrooms may present special problems for the person with dementia. If possible, try to assist the person when using a public bathroom.

Many products for incontinence are available in drug stores and medical supply stores. These products include adult disposable diapers, bed protectors and waterproof mattress covers.

ADDRESSING NUTRITIONAL NEEDS

In the early stage of Alzheimer's disease, eating habits usually do not change unless the person lives alone. In this case, there is a chance that meals are skipped or forgotten. There is also the risk of burning foods left cooking on the stove and starting a house fire. These are signs that the person probably should not be living alone any longer. In the meantime, foods may have to be purchased that are easy to prepare. Reminding the person by phone to eat may be sufficient. On the other hand, someone may have to prepare the meals. You may be able to arrange home-delivered meals through a local social service agency or catering service.

It is not unusual for a person with Alzheimer's disease to have a change in eating patterns in the middle and late stages. The person may no longer be aware of a mealtime schedule. Food may be either of increased interest, or of little or no interest. The person may forget how to cook and eat only a limited variety of foods. Whatever the case may be, a person with Alzheimer's disease may not be getting proper nutrition. Here are some suggestions for improving eating habits.

Mealtime at home

- ❖ Provide a quiet environment and regular routine to prevent confusion. Avoid over-stimulation with television, noise and too many people. You may want to play soft, relaxing music during mealtime.
- ❖ Try offering just one food at a time instead of filling the plate and table with too many things, which may be distracting.
- ❖ If the person is on a sugar-restricted (diabetic) or salt-restricted diet, try to keep certain foods out of reach such as ketchup, vinegar, oil, salt and pepper. A locksmith can put a lock on the refrigerator door if necessary. Putting masking tape near the top and/or bottom of the door may be enough of a hindrance. Childproof locks can secure cabinets.
- ❖ If a person has dentures, make sure they are tight-fitting. Loose dentures may cause choking or pain, making it difficult to eat. It may be best to leave loose dentures out until the person can be refitted for new dentures.
- ❖ A person may eat with their fingers. Offer finger food such as cheese, small sandwiches, kabobs, fried chicken, fresh fruits or vegetables. Sandwiches made with pita bread are easy to handle.
- ❖ Have the person wear a bib to prevent soiling their clothing. You may want to use a plastic or cloth cape that can be purchased at a wholesale outlet for beauty supplies.

Utensils

- ❖ Make sure the dish and placemat are different colors so they are more visible. To keep dishes from sliding, try putting a wet washcloth or suction cups underneath the dishes. Suction cups are available at medical supply houses. You may also want to try skid-resistant placemats.
- ❖ A bowl is usually easier to manage than a plate. However, a "plate guard" can keep food from being pushed off a plate. You can also use a "scoop dish" that can be purchased at medical supply stores.

- ❖ Travel mugs or spill-proof cups are useful for drinking soups and beverages.
- ❖ To help the person “catch on” to the motion of eating, place the fork or spoon in their hand, and help them guide the utensil to the mouth. Visual and verbal cues are often helpful, such as saying, “Put the spoon in your mouth” and then demonstrating this action.
- ❖ If hand coordination is a problem, try using utensils with large handles. You can purchase these or use foam rubber to build up the handles of your spoons, forks and knives.

Dining at a restaurant

- ❖ To avoid anxiety while waiting to be served, choose quiet, well-lighted restaurants where service is fast but friendly.
- ❖ Consider carrying printed cards to hand waiters that read: “My companion has Alzheimer’s disease and cannot always understand you. Your understanding and patience will be appreciated.”

Weight loss

As Alzheimer’s disease progresses, weight loss is sometimes a problem. The person with the disease may have a loss of appetite or difficulty chewing or swallowing. Most often, increased pacing and activity without appropriate food intake causes weight loss. Following are ways you can help increase the person’s appetite and the amount of food they eat:

- ❖ Encourage the person to eat high-calorie, nutritious foods. Offer high-calorie snacks such as protein milk shakes. You can purchase high-protein drinks and powders at any drug- store. Put pureed food in instant breakfast or high protein drinks. Let the person drink the food instead.
- ❖ Offer a multivitamin once a day.
- ❖ Double portions of breakfast food as the person will often eat breakfast, since it is the first meal of the day.
- ❖ Don’t skimp on fats. Use extra cooking oil, margarine, butter and mayonnaise in cooking and preparing food.
- ❖ Consult your physician if the person has significant weight loss, such as 10 pounds in a month.

Problems with swallowing

As Alzheimer’s disease progresses to the late stage, the person may no longer have the coordination to chew and swallow correctly, which can lead to poor nutrition and weight loss. If there is choking with each bite of food, there is a risk that the food could go into the lungs and cause pneumonia. These suggestions may ease problems with swallowing:

- ❖ Make sure that food is cut up in small pieces and is soft enough to eat.
- ❖ Ground or pureed foods may ensure safe swallowing. You can grind or puree most foods in a blender or a baby food grinder.
- ❖ Offer other soft foods such as ice cream, milk shakes, yogurt, cream soups, applesauce, Jello or custard.

- ❖ Thin liquids are most difficult to swallow. Remember these tips: Do not have the person use a straw. Instead, have them drink small sips from a cup. Milk may not be a good choice; it tends to get caught in the throat.
- ❖ Cold drinks are easier to swallow than hot drinks.
- ❖ A product called "Thick-It" is available in most drugstores. It can be added to liquids to thicken their consistency.
- ❖ Don't hurry the person. Each mouthful should be chewed and swallowed before the person takes another bite.
- ❖ Don't feed a person who is drowsy or lying down. The person should be in an upright, sitting position during the meal, and for at least 20 minutes after the meal.
- ❖ When swallowing, have the person keep their neck forward and chin down.

Some people may go through phases of having a poor appetite and then resume better eating habits. Try to make meal-time a social, enjoyable activity.

UNDERSTANDING BEHAVIOR AS A FORM OF COMMUNICATION

With any person the way we act and behave is really a form of communication. It tells those around us what we are thinking and what we are feeling. Along with what people say, their behavior and actions are an important indicator of their thoughts and moods.

People with Alzheimer's disease begin to have more trouble expressing themselves verbally. They are not always able to tell us what they are feeling and thinking. For this reason, the behaviors they exhibit really become an important way for them to communicate with those around them. Looking closely at their behaviors becomes our chance to better understand what the person might be feeling.

This might take a change in attitude on the part of the caregiver. Years ago it was thought that the behaviors exhibited by the person with Alzheimer's disease were an unfortunate and inevitable part of the disease process. It was thought that the best course of action was to try and stop the behavior without really looking at what might be causing the person to act in such a way.

We now understand that to best meet the needs of the person with Alzheimer's disease it is more important to look at all behaviors, both positive and negative, and ask what might the person be feeling to respond in such a way. If the behavior they are exhibiting seems positive we want to encourage that to continue. If the behavior they are exhibiting is negative and unpleasant for the person we want to learn why that might be happening and think of ways to reduce it from happening again.

When looking at the behaviors that someone is exhibiting a person takes on the role of an investigator. One must ask such questions as what might the person be feeling and why would they be feeling that way? Are there any factors that might be influencing the person? Some of these factors include emotional and physical well-being, environmental factors, and the approaches of others.

Emotional Well-Being

Our emotional well-being greatly influences how we act. When we are feeling down, overwhelmed or scared we will show it through our behavior. People with Alzheimer's disease often feel this way. Their self-esteem is often lowered because of the confusion and uncertainty they are experiencing. They can also become stressed easily if there is a change in routine. If more people are over to visit or if they are going out to a new location they can become more agitated or anxious. At times they might become scared or frightened.

Physical Well-being

Another factor that can influence how we act is our physical well-being. People with Alzheimer's disease are not always able to tell others when they are feeling uncomfortable or in pain. As family members we have to be very observant for any of the following physical problems:

- ❖ Negative reaction to medication
- ❖ Pain n impaired sleep
- ❖ Infections
- ❖ Dehydration and malnutrition
- ❖ Constipation
- ❖ Poor vision and hearing

Environmental Factors

Sometimes the environment can be confusing or overwhelming for anyone. This can especially be true for a person who is confused. Finding their way from one room to the other can be stressful and difficult. This is true even in a home where they have lived many years. Noise around them might be more than they can tolerate, such as TV, radio, and other's talking or laughing. You might need to look around your home and see if there is anything that could be adding to the stress of the person.

Approaches from Others

The final area of stress that can influence the person's behavior is the approach of others around them. If unrealistic expectations or demands are placed on the person it will probably add to their levels of anxiety. At times it can be difficult to remember that the person might not be able to do all the tasks that they had done before. It is not always easy to accept the fluctuation with this disease, where one day their abilities can greatly differ from another day. As caregivers we must keep in mind that this disease can make even simple activities difficult for the person to perform.

Also, sometimes a person's verbal response can add to the anxiety of the person with Alzheimer's disease. People with dementia are not always able to understand words said to them but they are very good at picking up on the mood of the person. If their caregiver shows that they are angry, frustrated or annoyed the person with AD often becomes aware of this. The most successful caregivers find ways to keep these emotions from the person. This is not always easy since these are often common emotions for a caregiver. It takes practice to see

what response is the most helpful for the person with AD. As caregivers we cannot be too hard on ourselves when we make mistakes.

By looking at what might be causing a person to be acting in such a way we will be able to have a better understanding of what the person with AD might be feeling. When we have a better understanding of what they might be feeling we get better at meeting their needs. For any caregiver the goal is to help the person with Alzheimer's disease to feel safe and comfortable.