

Module 6 - Day to Day with Dementia

Purpose: To provide person with dementias and caregivers who are in the earliest stages of dementia positive information regarding things they can do to help maintain function and prevent secondary behavioral symptoms

Intended use: Person with dementias in stages 3-6 of dementia

Introduction

When receiving a diagnosis of a dementing illness many fears arise. Families are often concerned about how to structure their day. Must everything change? Must we give up the things we have always enjoyed? Will the person become violent? Start to wander? How will we manage? The following module outlines the basic knowledge caregivers need for planning days throughout the illness.

Extra Disability

The person with dementia begins to have subtle changes in their ability to plan, tolerate stress, and interpret things in the environment as soon as the first symptoms appear. These changes strain the person's ability to function as they did in the past. However, there are certain things that will cause increased strain or frustration early in the disease and will eventually trigger dysfunctional or problem behaviors. We call this "Extra Disability." It means that the following things make the symptoms of the disease worse without making the actual disease worse. If they are attended to, the extra symptoms disappear.

The goal of care for people with dementia is to act in a role that assumes several things:

- People with dementia have symptoms that can vary enormously throughout the week or even day. So, they have times when they perform well, and others when they have more problems.
- The person with dementia is always trying as hard as they can. Asking them to "try harder" only produces more disability.
- The role of the caregiver is to "fill in the blanks" by helping the person with things they are unable to do at that moment.
- That said, as a caregiver it is extremely difficult to hear your person make mistakes and not remember. There is a normal response of wanting to correct the person, however it can result in an antagonistic relationship.

Things that produce extra disability (make symptoms of dementia worse) and must be taken into consideration when planning care.

Fatigue:

The biggest enemy of the person with memory loss is fatigue. People with brain diseases tire very easily -- because they have to concentrate so hard all the time. Try the following suggestions to prevent fatigue:

- Give the person a rest both in the morning and the afternoon. This may be just a quiet period or an actual nap. If the person naps, have him/her sleep in an easy chair, on the sofa, or on top of a made bed so they know when they wake up that the rest period was a nap -- that it is not morning all over again!
- Research has shown that letting a person sleep as late as they like will decrease late day confusion and night-time waking. This is a good idea unless the person tends to sleep all day and is up all night (reversing night and day).
- **If the person is waking at night DO NOT keep them up all day.** Forcing them to stay up all day can make the night waking worse!

- Avoid foods and beverages with caffeine. Try decaffeinated coffees, teas, colas, and pops containing no caffeine
- If you are planning a social activity or trip, make sure the person with dementia is well-rested both before and after the trip. Many families make the mistake of trying to accomplish too much during a day. Travel for a while, then stop and rest. See “The Travel Brochure” for tips on travel.
- Get to know the person’s “best time of day.” Use that time to visit friends, go to the doctor or dentist, or travel
- Plan activities that are of a shorter duration. Research shows that no activities, naps included, should last longer than 90 minutes. Instead of cleaning the house in a single day, spread the chores across several days to prevent the person from becoming overtired.
- During holiday gatherings or special occasions such as weddings or reunions -- when the person is away from home -- plan in advance a place and times when he/she can get away to rest during the activity.
- Many people with dementia go through a period where they sleep a great deal. If this happens, check for depression or boredom. If the person has no activities except television, or no one helps them to start an activity he/she will tend to sleep from boredom. If neither is present and the person is still sleeping at night, understand it is normal for the illness, specially in stages 6 and 7. This is a good time for you, the caregiver, to get things done, catch up on your rest, or indulge your own interests.

Change:

People with memory loss have problems with planning. The more they think about an activity, the less they are able to do it -- even though they could do it yesterday or can tell you how to do it! Help the person with dementia and decrease their frustration by doing the following:

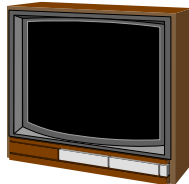
- Have a routine you follow during the day. While the timing of the routine is not important, the sequence of activities is very important. For example, if the person with dementia gets out of bed, has breakfast, and then bathes and dresses -- it is not a good idea to have them get out of bed, bathe and dress, and then eat breakfast. This produces frustration and anxiety that can accumulate throughout the day and produce increasing problems in late afternoon or at night
- When well-meaning family and friends suggest the person with dementia needs a change of pace, gently reassure them that this may not be in the person’s best interest.
- Redecorating the house, decorating for the holidays, moving, or even rearranging the furniture can produce problems. Before moving, redecorating or remodeling consult with a memory loss specialist at Banner Alzheimer Institute or the Alzheimer’s Association office nearest you. Seeking advice in the beginning can save many problems later.
- Keep holiday decorations simple. Avoid having many long holiday gatherings and parties with large numbers of guests. Simple, quiet festivities are enjoyed more by the person with dementia and do not result in behavior problems
- If the person demands to be taken home during a party or becomes rude to friends or children, understand this behavior is not aimed at the person. It is simply the person with dementia’s way of telling you he/she is tired or overwhelmed by the activity level, change in routine, and/or has become tired. Do not try to talk the person into staying until the end of the activity as this may cause behavioral changes for up to 2 days!
- Travel can be especially difficult. Plan trips with the help of a knowledgeable professional from the Banner Alzheimer’s Institute who regularly helps families manage problems associated with travel. Ask for a copy of the Travel Brochure, designed to help families who must travel with people with memory impairment.

- Occasionally you will plan trips or events that you know will trigger increased confusion. Expect the confusion. Plan to have extra help or medications on hand to see you through this period.

Overwhelming or misleading stimuli:

People with memory problems suffer the loss of ability to interpret what they see and hear properly. Noises and things they see may become distorted -- like a fun house on the midway at the state fair. This causes the person with dementia to become uncomfortable in crowds or in noisy settings. Groups as small as ten people can result in an angry outburst, a demand to leave, or rude statements -- especially if the person with dementia is tired.

- If the person wants to leave, it is a good idea to honor their wishes and leave the setting, or have them retire to rest for a while.
- Encouraging the person with dementia to continue to attend or stay at a social gathering may produce severe agitation or waking up confused that night. These symptoms may occur 12 to 24 hours after the event and are an excellent way to determine how much the person is able to handle.
- Use the person with dementia's requests to leave as an indication of how much activity, noise, and how large a group the person with dementia is able to tolerate.



- If the person with dementia begins to complain of people at home who aren't there--for example seeing little people or children-- turn off the TV, take down family pictures, and cover windows at night. Mirrors may have to be covered with roller shades especially in the bathroom. The person with dementia may not recognize their reflection and leave thinking a stranger is in the room.. It is best to call the Banner Alzheimer Institute and talk this over with a professional.
 - Television is a common cause of illusions and ideas about things that may be happening in the home. Many of us watch violent programs (such as murder mysteries) or sexually suggestive content (such as soap operas) without thinking much about it. The person with dementia may intuit that these things are happening in their home. Once these ideas occur they are fixed. The person can not be convinced this is not reality. So, we follow the following rule for people with dementia:

Never watch anyone on TV who you would not have to your home for dinner!
 - There are videos of TV programs that are more consistent with your person's values available at video stores and large discount markets, such as Wal Mart. There are also TV cable stations devoted to older situation comedies, westerns, and other less-graphic material.
 - Sporting events can be a great source of entertainment but be very careful of those that focus on human contact such as wrestling, boxing, or extreme sports.

Television should never be the primary source of activities and should not be used as a babysitter!
- If the person begins to use places other than the toilet for elimination, consider that they think their mirror image means the bathroom is occupied.
 - Purchase a simple roller-type shade and cover the mirror when no one is using it.
 - Then try coloring the water in the toilet bowl.
 - Redirecting the person back to the toilet.

- If the person is a man, you can try floating a few floating cereal bits (such as Cheerios) in the toilet for them to sink.
- If the person is a farmer or rancher, hang a landscape print over the toilet at eye level.

If arguments or paranoid behavior occurs

If the person with dementia begins to develop ideas that people are in the house, becomes suspicious that people are doing things behind his/her back, or tell stories you know aren't true, **Don't argue or correct them.** Recognize that the person's brain is "playing tricks," and the illusions and beliefs are very real to them. The person with dementia believes these statements. Correcting the person will simply convince them that you don't know or care about what they are experiencing. It is best to reassure the person of the following:

1. They are safe
2. You have taken care of the problem or your intention to take care of it. (This is a statement, you do not necessarily act on it)
3. You understand the person with dementia is concerned and upset by what they are seeing or hearing.
4. If the agitation escalates and does not wear off call 911. You may be in danger.
5. If the person with dementia begins to look for a weapon get to a safe place, such as locking yourself in the bathroom, and take the phone. Call 911.

Loss of meaningful activities: Activities are the single most important aspect of dementia care!

Activities define who we are. When the person with dementia loses the ability to drive, work, mow the grass, cook, or perform other meaningful tasks, depression or anxiety may result. It is important to substitute old cherished activities with similar simpler activities.

- If there is an occupational therapist in your area, talk with either an occupational therapist, recreational therapist, or activity therapist to help design replacement activities. If no therapists are available in the hospital in your area, contact a nursing home and ask for the activity director.
- There are numerous books and ideas for activities. A resource list is provided at the end of this module. The best activities are varied and involve several types of things:
 - Day to day activities – Includes bathing, dressing, eating, cleaning up, and routine chores
 - Exercise – Exercise can be walking, gardening, vacuuming, dancing, or doing chair exercises. Twenty minutes of exercise five times a week is recommended. Research suggests that regular aerobic (walking etc) exercise may slow the disease progression.
 - Cognitive or mental exercises – These include puzzles (such as find the word puzzles), reading (if possible), working on projects, such as sorting family pictures with you. If you need activities that stimulate but are not too challenging look in an educational toy store where there are cognitively stimulating activities sorted by developmental level. Caution must be taken to assure that the activities do not look "childlike as the person with dementia is still an adult.
 - Socialization
 - Spiritual activities – If the person has always attended their religious or spiritual activities, this will remain meaningful
 - Outings – Many people with dementia enjoy eating out, flea markets, shopping, and other activities. As long as they enjoy it and do not have behavioral issues the day after, these activities should be pursued.

- The Arts – People with dementia often enjoy music, creating art, and other activities they have never tried before. Creating visual art, such as painting, is best done in a structured setting with other people of similar abilities
- The primary role of activities is to allow the person with dementia to focus on remaining abilities and strengths, thereby enhancing self-esteem.
- If you have adult day programming available, use it. It can provide social contact and meaningful activities for the person with dementia as well as respite for you.
- Have the person with dementia help around the house. Many people can manage simple activities such as dusting, sweeping, table setting, sorting, and helping with simple cooking tasks late into the disease. Think of the activities as therapy. Do not evaluate the results. If the person's performance is incomplete or sloppy accept it is part of the disease process and recognize that the activity remains valuable for your loved one.
- Look at activities that may be too dangerous such as using power tools, hunting, feeding livestock, working with flammable tools, and try to replace them with safer activities. Many men who have not had hobbies are able to learn simple repetitive tasks with supervision such as painting, latch hook rug making, cooking, and simple woodworking.
- Pets, gardening, and musical activities often produce a high degree of satisfaction and offer good exercise.
- In very late stage disease visual stimulation such as crystals in a window can provide some stimuli. Music and reading aloud to your loved one is often a satisfying and reassuring activity even late in the disease
- Use videotapes to your advantage. Obtain videos of old television comedies, tape favorite sporting events, and have videos of family members. Avoid stories that include violence, murders, or cartoons.

Talking about the disease and depression

The vast majority of people with dementia know that something is wrong. They know that their memory is failing. People with dementia go through a process of grieving similar to that of their family. Research shows that when family refuses to talk with the person about their illness, the person with dementia is likely to become paranoid as family members begin to avoid them. Talking about the illness keeps the person on the "same side of the table" as the family. The illness is the problem, not family members who must take things such as driving.

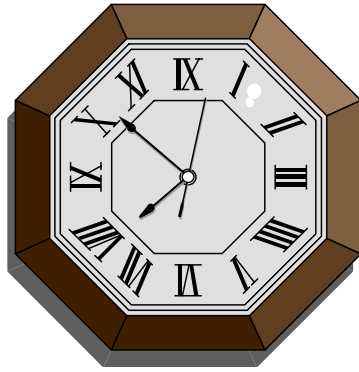
- Allow the person with dementia time to talk about their losses. Grieving is normal -- even desirable.
- If the person develops a low mood that lasts for more than 3 weeks, affects sleep or appetite, have him/her see their primary doctor about treating depression. Depression is a common occurrence in dementing illness.
 - Failing to treat it will make the person's dementia symptoms worse and decrease their quality of life.
 - Depression is treated with medications usually prescribed by the primary care provider. The medications given take about three weeks before you see the real effect.
- Discuss the disease process with the person with dementia so he/she can understand why activities are being lost and they do not think, "they are going crazy." If the person is losing driving privileges, either you or a health professional should tell them the reason. If no one discusses the problem with the person with dementia, they are likely to develop paranoid or suspicious ideas. While you may not choose to use the term "Alzheimer's disease" most person with dementias can understand the idea of "brain disease," or "dementia."

- It is helpful to remember that this is a chronic (long lasting) illness like heart disease, diabetes, or cancer. We can treat the disease and the person may live for 15-20 years.
- People with dementia often have a fear of abandonment. Reassure the person that you intend to see them through for the remainder of the disease, but do not make promises you may not be able to keep. One example is the promise never to put someone in a residential facility. You may need to place the person at some point, but you will always be there for them.
- The person with dementia may become angry or deny their memory loss. If this happens, drop the subject for a time. The goal is not to get the person to admit the memory loss, but to help them to understand why these things are happening. Denial and anger are a normal part of the grieving process.
- Do not assume that ignorance of the disease process will lead to a happier person with dementia. Also, do not think that telling the person about the memory loss will “kill them,” or cause them to “give up.” This is very rarely the case. Trying to hide the illness from the person with dementia becomes increasingly difficult and strains your relationship with the person with dementia.

Creating too much demand:

Many caregivers feel they need to exercise the person with dementia’s brain, testing every day and pushing them to achieve. In addition, it is unnerving for family members to hear the person make mistakes and not correct them, but it is essential.

- Think about how you feel when someone tells you you’ve made a mistake. Being corrected feels pretty bad. The person with dementia with memory loss is constantly confronted with their mistakes, which is pretty uncomfortable. What we try to do is make the person with dementia feel comfortable with the knowledge they have -- as long as they are safe
- First, don’t try to exercise the brain. Activities are the exercise the brain needs. People with memory loss are not lazy, they have a disability that is, in many ways, like an amputation. We have to assume they are working as hard as they can at any given moment with the abilities they have left at that time. People with memory loss have good days and bad days. Accept the person with dementia’s changing abilities each day -- or hour-- as the best the person can do right now.
- Avoid quizzing the person: “Do you remember me?” “What is her name?” “Remember what we did yesterday?” Life becomes like a constant test for people with memory loss and we don’t want them to feel as if they have failed that test again and again.
- If the person becomes upset, try to distract them rather than confronting. If that does not work and the person is safe, walk away and let them forget



- Do not announce things in advance. People with memory loss have problems figuring out time. They become upset and fearful about schedules -- especially doctor visits. Announce activities at the last possible moment.
- Let the person with dementia forget. If you lose your temper, the person with dementia refuses to bathe, or there is a behavioral outburst, leave the person with dementia alone and approach them again later. The outburst will probably have been forgotten
- If the person with dementia has forgotten how to do an activity, help them with it. Try to “talk them through it” one step at a time. Don’t tell them to “think about it.” Thinking about it only worsens the problem. Use distraction instead. Distraction is simply changing the subject. Examples include: moving on to another task; giving the person a glass of juice or water; making a phone call to a friend; looking at family pictures in an album; or reading a letter aloud. Let the memory loss work for you. If a letter, joke, or other distracter is helpful once, don’t be afraid to use it again and again.
- Sometimes your loved one’s forgetting can actually be useful. If they become upset about something, reassure them and don’t bring it up again.
- Whenever possible give the person a choice. “Do you want a bath or a shower?” “Would you like a person to stay with you in the home or to enroll in an adult day program?” **We avoid the term “Do you want to.....?”** The person with memory loss will tend to answer “No!”
- Don’t be afraid to use humor. While we are not laughing at the person with dementia, some things will be funny. Learn to laugh at those things and at yourself without feeling guilty. The more humor you can maintain, the easier your job as a caregiver will be.

Illness:

If the person with dementia is not feeling well, has pain, is coming down with a cold, has a medication reaction, or an infection, you will probably see a sudden onset of problem behaviors and confusion that do not go away with rest. If this happens and the person with dementia does not improve in an hour, complains of pain, shortness of breath, has bleeding, or vomiting you need to see the doctor as soon as possible – even if it means going to the emergency room..

Think about the following common problems:

- Has the person been drinking at least one and a half quarts of liquid each day? Are they urinating frequently? Does their urine smell strong? Urinary tract infections are very common causes of agitation.
- Does the person have arthritis or another painful condition? Is the person with dementia on his/her feet all day? Does the person “hold” or protect a part of his body? Even though the person with dementia may not complain of pain, we need to think about it. Ask the doctor for a medication you can use to relieve pain and use it regularly for **mild** pain. If the pain is allowed to become severe, the pain medication will be ineffective. If the person begins to moan, yell, or scream, suspect he might be in pain.

- Worry about constipation. Make sure the person with dementia receives adequate fiber in their diet, but avoid laxatives and enemas. A good proven source of fiber is two oatmeal raisin cookies with milk each afternoon. Read labels when thinking about fiber. Breads should have a minimum of 3 grams per serving.
- Have the person's prescriptions, over-the-counter medications, vitamins, and herbal preparations checked regularly by your doctor or pharmacist.
- Avoid alcohol intake as it can worsen memory permanently. Many people with memory loss over-react to alcohol. Try alcohol-free beers, wines, and mixed drinks with as little alcohol as possible. If the person with dementia becomes upset, try mixing more and more dilute drinks. Some caregivers add water to liquor bottles after their loved one goes to bed. Ask your physician to tell your person with dementia not to drink alcohol.
- Talk with your physician about health and preventing illness. Ask about flu shots, the vaccination for pneumonia, and updating the tetanus vaccine if needed.
- Diet and nutrition may become a problem. Have your person with dementia take a simple multiple vitamin daily -- especially if they are not eating a balanced diet. Become concerned if the person with dementia begins to lose more weight than 6 pounds in 6 months. Unless the person is on a weight reduction diet, weight loss greater than 6 pounds in 6 months is cause for alarm -- no matter how heavy they were before. See your doctor. Consult with a dietitian. If the person refuses to eat, try different foods that are high in calories, and contact a helping professional. Instant breakfast drink in whole milk can be used as an inexpensive, tasty, and fully effective nutritional supplement.

When a Problem Behavior Occurs:

You have used these recommendations, but despite your best efforts, one day your loved one begins to scream at you, doesn't recognize your home, or wanders away. There are some tips for managing these stressful events:

1. Recognize the problem is temporary and will pass
2. Give the person something to do
3. Don't argue with or confront the person. Treat the person as if he/she is frightened. Tell them you understand and intend to help.
4. Get the person to a quiet place where he/she can rest briefly.
5. If it is the middle of the night, try to give them a snack and get them to an easy chair
6. Understand that these episodes are similar to a panic attack. The person with dementia is scared to death. If you him/her like they are frightened, the attack should begin to subside.
7. If the person does not recognize his/her home, try driving them around the block, or reassuring them that this is the place where you will spend the night (implying it is a hotel). Reassure them you will go home tomorrow. Apologize that they are upset. True, you have done nothing wrong, but you ARE sorry the person is upset.
8. Try calling one of the person's children to reassure the person with dementia. Sometimes a call to a family member can be reassuring when all else fails -- especially if they are not recognizing you.
9. If the episode does not resolve within an hour or so, contact your physician or take the person to the nearest urgent care center or emergency room. Do not try to get an agitated confused person into your car. Call the paramedics.
10. Do not blame yourself for this episode. These agitated and confused episodes are a normal aspect of the disease. They will occur to even the best of caregivers.
11. Do not become upset if you get angry. Anger is a natural response to stressful and unpleasant situations. Learning to manage these behaviors is a matter of trial and error. With practice and understanding you will become more skilled.

12. Finally, if the person comes at you aggressively, tries to use a weapon, or leaves the house – particularly if he/she intends to use the car – call 911. This is not something you should try to manage alone.

NOTES:

Key Points for Day to Day Management

1. The person with dementia experiences both the normal symptoms of the illness and from time to time “extra disability.”
2. Extra disability can be prevented by managing the following triggers:
 - a. Fatigue
 - b. Change of routine or environment
 - c. Overwhelming or misleading stimuli
 - d. Feelings of loss from declining abilities and activities
 - e. Too much press from others or themselves
 - f. Physical illness, pain, or medication reactions
3. If a problem behavior occurs, try to figure out what was happening up to 24 hours before and spot the trigger.
4. If the behavior does not resolve in an hour or so or with rest contact the person’s physician
5. If you are in danger, call 911