

Module 7: Identifying and Managing Problem Behaviors, Diffusing Arguments, and Violence

Purpose: To introduce patients and families to commonly encountered secondary behaviors, how to prevent them, and manage them once they have occurred.

Intended audience: All patients with stage 4 or greater disease and their families

Introduction

Diseases that cause memory loss --- including Alzheimer's disease, Parkinson's disease, and strokes --- have a variety of symptoms that can baffle and overwhelm family members. Some of the most challenging and frightening problems rarely occur early in the disease but may "pop up" when it is least expected as the disease progresses.

Examples might include the following:

- Demanding to leave during an activity or event they had been looking forward to
- Waking up in the middle of the night to get dressed and start the day
- Not recognizing familiar settings, home, or family late in the afternoon
- Accusing family members of stealing items the person has hidden -- or blaming "outsiders" for taking things
- Threatening family members with physical violence
- Becoming irritated or belligerent late in the day
- Refusing to bathe, go to the doctor, or out socially for no apparent reason
- Walking away from home or getting lost
- Pacing back and forth without stopping
- Telling stories you know aren't true
- Thinking there are extra people or children in your home
- Seeming selfish

These behaviors may seem mean-spirited and purposeful, but they are simply symptoms of the person's dementing illness. These behaviors are mostly normal and expected in mid-disease. It is important to realize that the person can not control these sudden behavior changes, but you can help to prevent or minimize them. While not everything works all the time, we can eliminate much of the "acting out," behavior by making simple changes in our behavior and the environment. The changes help the person to succeed. Unexpected changes in behavior are often triggered by things you can control - - once you know how. MAPS Module 6, Day to Day with Dementia describes how to prevent many of these behaviors in detail.

The purpose of this module is to provide an overview of the most common problem behaviors (also called "secondary behavioral symptoms") in order to help manage them.

When a Problem Behavior Occurs:

You have used the recommendations in Module 6, but despite your best efforts, one day your person 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. Make sure you are safe until it passes.
2. Don't argue with or confront the person. Treat the person as if he/she is frightened or panicked. Tell them you understand and intend to help.
3. Give the person something to do. Ask the person to help you do something.
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. Do not try to convince the person that it is night by showing them it is dark outside.
6. If the person does not recognize his/her home, try driving them around the block, or reassure them that this is the place where you will spend the night (implying it is a hotel). Reassure them you will go home tomorrow.
7. Try calling one of the person's children to reassure the person. Sometimes a call to a family member can be reassuring when all else fails.
8. 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 paramedics.
9. Do not blame yourself for this episode. These agitated and confused episodes are a normal aspect of the disease beginning in stage 5. They occur even with the best of caregivers.
10. 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 anger will be replaced as you learn to manage and prevent these episodes.

Most important these episodes represent the person's fears and/or unmet needs. Often caregivers feel that the person does not know they have the memory loss and is unaware of their confusion. Thus, caregivers try to avoid discussing the disease for fear of upsetting or terrifying the person with the disease. Research shows that if people with dementia are not given the opportunity to talk about the illness, their fears, and grief, they become paranoid. It is important that the person be given time and attention to express him/herself.

Special Problems:

The following section deal with approaches to problems that are commonly encountered when caring for people with memory loss. While there are no definitive answers to these problems, the approaches suggested may help.

1. Bathing

Many people go through a phase where they either refuse to bathe or tell you they have already finished their bath. This can be frustrating, especially if the person develops body odor. The first (and most important) thing to remember is that no one ever died from not bathing. Many older adults are modest about disrobing, or become afraid of bathwater or the shower. Some of the following suggestions have been helpful:

- Let the person choose the time of day to bathe
- Make sure they have a warm towel and fluffy robe to prevent chilling.
- If the person bathes well at the sink, that may be enough. Many older adults become afraid of falling in the tub and bathe while standing or sitting at the sink for the rest of their life.
- Towel baths can help the institutionalized person accept bathing.
- Remind him/her of a special occasion they must be clean for (e.g., “we can’t go out for lunch until you bathe”)
- Associate a pleasant experience with the bath (such as a chocolate treat or music)
- Make sure you check the temperature of the bathwater or shower to prevent freezing or scalding.
- Color the bathwater or use bubble bath
- Make sure there is a non-skid mat or surface in the tub and that bathmats are changed every few months as hard water can cause them to lose suction
- Try a hand-held shower head so water does not hit the person’s head
- Allow the person to bathe with underwear on
- Sing during bath-time to relieve the tension or have some soft music in the background.
- Compliment the person after the bath
- Don’t take refusals to bathe personally Sometimes a bath aid can do what the caregiver is unable to

2. Wearing the same clothing day after day

This is an indication that the person can not handle change and is normal for people with memory loss. Purchase several identical outfits when shopping. Then, when the person takes one set of dirty clothing off, remove it and replace with an identical set of clean clothing. Make sure you have a picture of your loved one in this clothing in case they wander. You will be able to tell the police exactly what the person is wearing.

3. Hiding things

Hiding and losing things are the most frustrating aspect of the disease for many caregivers. Understand that hiding things often represents a concern about theft. Things will be hidden. It is important to minimize the loss of money and valuables.

- Remove valuables from the house whenever possible. Remember, these possessions still belong to the person and can not legally be dispersed using the person’s will. Take larger valuables such as the family crystal, silverware, and china, and pack them away. Label the carton “books,” or something that does not attract attention and place them in a safe area, such as a little-used closet or basement.
- Place jewelry not used daily in a safety deposit box.
- Take jewelry worn daily and have it appraised. Have the jeweler remove the most valuable stones and place them in a safety deposit box. Replace the valuable stones with cubic zirconium and return to the person.
- Never ever send jewelry you would mind losing with the person to a nursing home or assisted living facility.

- Put “clappers” on house and car keys so they beep when lost, have a routine place, like a basket at the door and remind the person to drop keys in it when entering the home.
- Get to know where some of the more common hiding places. Families report hiding money, keys, jewelry, medications, and many other things in the following locations:
 - under the mattress
 - in the pages of books
 - in the hems of curtains
 - under the paper in back of pictures or mirrors
 - under pillows
 - in food containers
 - in the freezer
 - behind bricks in the basement
 - in breakfront cabinets
 - wadded in tissues in toilet paper cardboard cylinders
 - in the trash

It is important to remember that things will be lost. Make sure that there are duplicates of keys and other items. Also, losing the car keys is an excellent way to have your loved one stop driving. This is one example where you may decide to let the keys “stay lost,” and not volunteer another set.

4. Fear of abandonment/refusing help

Fear of abandonment is one of the most common issues people with dementia face. They know what is happening to them and worry they will lose the people they love and depend on. Also change is increasingly frightening as familiarity slips away, thus many people with dementia refuse any suggestions.

Many persons refuse to go to adult day programs or to allow in-home respite services. Persons become dependent on their caregivers to remember when they can't and become nervous and upset when their caregiver is not around. This can become so severe that the caregiver is unable to have even a moment alone, including to go to the bathroom.

The best defense against this is a good offense. Have your loved one go to day programming. Despite what the staff recommends, the caregiver should stay with the person in day care for 2-3 days until the person “gets to know” the staff and routine. If you feel uneasy about the day care setting, are upset that your person is being put in a place with people more affected than he/she is, perhaps another family member might help as your ill-at-ease will be felt by the person with dementia. Remember research shows that people who attend adult day programming stay at home longer and adapt better to new circumstances, especially placement.

Have extra help in the home as early as possible so the person is used to having others around. A cleaning person is a good starting place. Make sure that family members participate in care on a regular basis and, if possible, friends take the person out whenever possible.

If the person becomes enraged when a service provider or family member is used for respite, understand that this is not uncommon. Insist that you need your time and space. Gently reinforce that staying alone or going with you is not an option. Insist that you will try to find respite workers that the person likes.

The first time or two the person attends day care or has a new respite worker, stay with him/her during the event. As your loved one becomes accustomed to the day program or respite worker, anger will subside. Successful adaptation to respite will keep your loved one at home longer and will help to keep you from feeling trapped.

5. Aphasia (Loss of ability to use and understand language)

Loss of language abilities are a usual part of memory loss. Loss of reading comprehension generally occurs first. One of the ways to determine this is if mail starts to pile up or the person begins to pay anything that even resembles a bill. Another clue is when the person either stops reading the paper or can't tell you what they have read.

When the person starts to stumble over words, it is important to understand that they also have trouble understanding what is being said. Talk more slowly using simple phrases. Give the person extra time to respond. Use gestures and point to objects whenever possible.

If the person begins to use words that don't make sense, often called "jargon" or "word salad," try to find bits and pieces that relate to the person's world. The person may have good understanding of the world around them, but may simply not be able to express him or herself.

It is acceptable to explore potential meanings with the person unless frustration begins to rise. If he/she becomes frustrated, distract them to another task and try later. Do not be surprised if frustration and decreased inhibition might result in the use of swear words. These words are simply that: words. You do not want to draw conclusions based on their use. A single consultation with a speech pathologist may be helpful to develop communication strategies.

If the person originally spoke a different language, it is expected they will return to that original language. If no one in the family speaks that language sometimes an interpreter might help – although the person often is aphasic in their primary language too.

It is important with all people with dementia to be careful about voice tone and body language. Frequently people with later stage dementias will get the majority of their interpersonal communications from body language and voice tone.

If the person develops slurred speech or problems swallowing, speak to your physician immediately. The person may run the risk of aspirating (breathing it into their lungs) food or saliva.

6. Made-up stories

One of the more frustrating effects of memory loss is called “confabulation.” People with brain diseases, especially those that cause memory loss, tend to have their brains “fill in the blanks” when they can’t remember what happens. So, the persons come up with stories that they believe are true.

Confabulation is not a lie. It is a story the brain makes up. Trying to correct the person leads to anger and frustration for you both. A good rule is that anything the person says is fine – as long as safety is not compromised.

7. Repeated Questions

Persons ask repeated questions for several reasons:

- they can’t remember asking the question;
- they have no sense of time; and
- the question they are asking is not really what they want to know

When your loved one asks a question over and over, most often it has to do with when or where something will happen. These questions can become obsessive. There are two rules for these questions:

1. Never announce anything more than 24 hours in advance because it precipitates obsessive questions.
2. When a question is asked more than once or twice, ask “why are you asking?”
3. Then address the underlying concern.
4. Example:
 - The person asks “What day is it?”
 - You ask --“Why do you want to know?”
 - The person says “I don’t want to miss church.”
 - You answer “I will make sure you get to church on Sunday.”
5. Another strategy is to write the answer on a file card and have the person carry it in his/her pocket. When the question is asked you direct the person to read the card.

8. Wandering, pacing, and eloping

Wandering is a common issue with Alzheimer-type dementias. It involves repeatedly walking, almost aimlessly, often getting into things and rummaging. Most people with dementia will wander at one point during the disease. While it is annoying, it is generally harmless unless the person attempts to leave or falls. It is important to put things away that might become broken and remove anything that might cause the person to trip, such as throw rugs or exposed electrical cords. Probably the best way to stop someone from wandering is to redirect them to activities such as music, crafts, helping you cook, or a busy box. See the module on activities for suggestions.

Pacing is continuous walking back and forth, usually at a brisk pace. People who pace may not stop to eat or participate in activities. And, both people who wander and those who pace are at high risk to elope. Secure doors when unattended and make sure these people have Home Safe Bracelets from the Alzheimer’s Association

People who pace should be treated with regularly scheduled pain medication and have new shoes every few months as pain will worsen pacing. Their health care provider will recommend the most appropriate pain control.

Another trick is to strategically locate a recliner near an object of visual interest such as a bird feeder which will encourage the person to stop and rest. People who pace and/or wander tend to do well in adult day programming, plus it provides the caregiver much-needed respite.

Eloping is leaving a specific area without the knowledge and approval of the caregiver and poses risk to the person with dementia. Thus a person who takes an afternoon walk is not eloping. About 61% of people with dementia living at home will wander away, compared to 23% of people living in nursing homes. Caregivers must consider their loved ones at high risk, even though they have never left home before.

Some precautions are keeping doors and windows locked when not in use. Place slide bolts at the bottom of exterior and basement doors. The slide bolts will need to be easy to open, yet few people with dementia look down to find them.

9. Waking at night

Coping with Violence: If Your Loved One Changes

A caregiver under siege reported:

“It is like a switch got thrown yesterday and all h- -l broke loose. He even seemed to have the urge to hit me when I was helping him get dressed today.”

Aggression can be a normal part of dementing illnesses. It can occur for many reasons, including extra demand, psychosis, a non-Alzheimer presentation, and/or premorbid personality traits. While real physical aggression is relatively rare, verbal aggression or belligerence is relatively common. People with dementia become depressed from time to time, get frustrated, or may not see their deficits as clearly as their caregiver. And the person with the disease is also going through the grieving process, which also involves anger.

Verbal Aggression

People with dementia who are angry don't always become violent or aggressive, however, care should be taken to diffuse verbal aggression before the situation escalates. Some of the more common techniques for diffusing verbal aggression include the following. Remember, the goal is to get on the same side of the table as the person and regain emotional support. You have to suspend your previous notions about right and wrong, and just go with making peace:

1. Agreeing – It is impossible to argue with someone who agrees with you. You can agree by seeing someone's point. For example:

Person: “I want to drive and you won’t let me. The doctor says I can’t drive. What does he know? Give me the car keys NOW!:

Caregiver: “We can’t have you drive with your memory loss, but that is so awful. I can see why you are angry. It is unfair this should happen to you”

You don’t have to give in, but you can acknowledge their feelings and put yourself in the same position. You can see the person’s point of view. It isn’t fair.

1. Apologizing – Now I know you haven’t done anything wrong and you shouldn’t have to apologize, but again, we are diffusing an argument here. You can not argue when a person is being contrite:

Person: “You have having an affair. You snuck out while I was napping and slept with the neighbor!”

Caregiver: “Oh (name), I am so sorry you think that! How hard this must be for you. Know that I would never do anything to hurt you. I love you . I am so sorry you feel this way. How can I make it better?”

Of course you didn’t have an affair, but one of the person with dementia’s biggest fears is abandonment. They know what is happening – even if they can’t say it and fear having to leave their home and family. Thus the charges of infidelity are common. When you are apologizing, notice you are not admitting guilt. You are saying you apologize for the way the person feels.

2. Playing dumb – “I don’t know anything about this. Tell me more? How could this have happened? I don’t understand?” These buy a lot of calmness

3. Avoid trying to reason and explain. The person’s “reasoner” is broken.

4. Back off and let time heal the wound.

Physical Aggression

While certainly not a normal part of a dementing illness, violence occasionally becomes a problem. When it occurs caregivers often report mixed feelings of disbelief, embarrassment, guilt, shame, and more than just a bit of denial.

When you have a loved one who is aggressive towards you, this is a crisis. Suspend everything until the episode passes. This is not the time to get someone dressed for bed or in the morning. This is not the time to insist on a shower. When a crisis presents, you want to back off and stay back until help arrives -- whether it be medication, a hospitalization, an ER visit or whatever.

It is sort of the idea that when the house is on fire, you don't want to finish breakfast and get dressed before you call the fire department. In a behavioral crisis there are several essential steps:

1. Step back. Suspend cares until the crisis is over. Do only what absolutely HAS to be done, such as food and getting in any mood controlling medications. If you try to intervene with normal activities you are increasing the risk to you and your loved one.

2. Use care in body language. Make sure you always approach from the front. Do not turn your back. And make sure you give the person plenty of space. Turn OFF TV, radio, and stop any extraneous stimuli. Just for now take down family pictures and cover mirrors. This is a crisis and needs special care. Talk in a measured low soft voice. If you have to give directions, make sure they are simple declarative sentences. ("Give me the knife" or "Put the knife down.")

3. Do not think because the person calms after a while that it won't happen again. Two basic principles of violence:

A. Violence episodes are time-limited because of the energy expended.

B. As soon as the person regroups their injury and there is a trigger (in the case above it was hallucinations), the violence WILL reoccur.

C. Untreated violence goes from bad to worse. It does not get better on its own. In every episode of an injured or murdered caregiver, there were warnings...but the caregiver chose not to heed them, often out of disbelief that their loved one would never do anything to hurt them. This is not your loved one acting here. This is disease and it needs quick and effective treatment.

4. This is not a time to let family "vote" on a solution. Much of the serious injury I've seen happened after the family told the caregiver that "it wasn't that serious, "dad/mom will get over it," "Dad would NEVER try to hurt you Mom," or "Gee Mom, you are just overreacting."

5. Get help immediately. Do not stay alone in the house with a violent person. The person is in a panic mode and cannot be counted on to inhibit any impulses. Recognize the danger and call the doctor.

A. If you can't get the doctor within an hour, call 911 and head for the nearest ER where the person will be sedated. Once at the ER, DO NOT MINIMIZE THE EPISODE!!!! "Gee, I think it only happened once, and I probably caused it because I tried to give him applesauce for breakfast."

B. Make sure you have a prescription for a mood controlling medication and a psychiatry appointment for follow-up in the next day or two before you agree to take the person home.

C. Many times the police coming is reassuring to the person as he/she is terribly frightened. The uniform can work wonders. Do not be embarrassed to call BUT if the police think the episode is over because the person calms for a few minutes, forget that thinking. As soon as they leave there is a good chance, an excellent chance, the fear will start again. Insist on an ER visit.

6. If you live alone with the person, make sure you have a Lifeline (panic button) so you can call for help. Persons who are violent rarely hand you the phone or act out in close proximity to the phone. Moreover, most could not dial for help in an emergency

7. Act defensively. Plan an escape route. Lock yourself away from a violent person and take the cordless phone. Never be without your cordless phone.

A. The caregiver in the closet phenomenon may seem absurd, but I'd rather have my caregiver in a closet with a cordless phone than out trying to fend off a person who is out of control.

B. If the person is violent it is far more likely to start at night. Move to another bedroom and make sure you can lock it in case the person comes after you. Two of my caregivers woke to find their loved one standing over them and beating them.

C. Make sure that you are at least standing up if the loved one wakes you. Get out of the bedroom you share. This alone could save you serious injury. A person in this situation is not thinking about the warm snuggle of a spouse or even abandonment by a spouse. They are fearing for their lives and you are part of the problem.

8. Remember, anything can be used as a weapon. There should be no guns in the house at all, not even in a locked cabinet. Fireplace pokers and knives should be stored out of sight. Your loved one is panicked at this point and may use a book, alarm clock, letter opener, or even a small table to injure you. Minimize potential weapons in the house and make sure you watch for anything that might be used. Never turn your back on someone who is violent.

9. **DO NOT REFUSE MOOD CONTROLLING MEDICATION!** There is this myth that if we are only good enough, only kind enough, the person will respond. While there are few persons who become violent, you need to treat it medically. Worry about tapering the medications after a few weeks of good behavioral control.

10. **DO NOT BLAME YOURSELF.** This just happens some time. No one is going to think it is you that caused this. Do not try to avoid treatment because it might be socially stigmatizing. It is better to seek help in a timely manner than to have your loved one become remembered as ____, who injured his/her family!

11. Realize that if it happened once, it **WILL** happen again.

12. Never never let an angry or violent person drive as the car can/will become a weapon. If the person takes the car to go out looking for a real or imaginary enemy. Call the police to stop them if you have to.

13. Do not rule out a psychiatric admission. Go for the best center you can find and let them treat the person, which may mean a brief period of zombification. make sure you play an active role in treatment, not by refusing medications but by asking "What now?" If your loved one is zombified, you can't take them home like that, but also recognize that there

are some people who cannot be let up from medications. Know that if you have someone with Lewy Body Disease, you cannot stop and start the medications or even try to taper a dose that is effective. With Lewy Body disease, once you taper and the symptoms start again, there is an excellent chance the higher dose will no longer work.

Last---- If you have any inkling of aggression, give a copy of this to your family and doctor. That way they know you are not being crazy or overreacting.

Source: Hall, G (2000). *As Memory Fades*. Iowa City: University of Iowa.