



A Road Map to Supporting Patients and Families with Behavioral and Psychological Symptoms Associated with Alzheimer's Disease

Why is it important to have a plan when supporting someone with behavioral symptoms associated with Alzheimer's Disease (AD)?

Understanding behaviors and symptoms that may occur during the course of the illness will help families prepare for difficult situations. It will not make dealing with issues less challenging, but will reduce stress on the patient, caregiver and family member facing AD. Behavioral symptoms can occur anywhere: in the home; where routine care and support is provided; visiting with friends and family; or during medical care and treatment. Having a plan with approaches to manage symptoms is the best strategy. Planning requires good communication between patients, family members and the medical team, as well as education on what happens to individuals as the disease progresses. This booklet does not contain all the answers, but provides supportive information and resources. Remember, you are not on this journey alone.

When should I talk to my doctor about behavioral and psychological symptoms associated with AD?

It is critical that families have information and education before symptoms begin to occur. Behaviors such as forgetting information, people, recent events, repetitive statements/questions, confusion, depression, apathy, poor self-care, anxiety, anger, aggression, sleep disturbances and wandering are all expected and may occur in someone with AD. Each individual will exhibit behaviors differently during the course of the disease. Behavioral symptoms are sometimes apparent prior to receiving a diagnosis. Some behaviors may have devastating effects if untreated and can contribute to more rapid disease progression, leading to earlier nursing home placement, accelerated decline, increased health care needs/costs, and reduced quality of life. Planning for the management of these issues should be addressed early in the course of the disease. Talking with your doctor about what to expect and the resources available to support you is an important first step.

Aging & Memory Loss Road Map Series for Families/Patients

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

IV. Prevention

V. Behavior Management



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When should a new diagnosis of AD be communicated to family?

It is important to tell family and friends that you have a diagnosis of Alzheimer's disease and to acknowledge it is a disease that will affect the entire family. By doing this you reduce stigma and begin to educate others about the fact that AD is a chronic debilitating brain disease. You prepare the family for expectations that lay ahead. This can help begin the discussion on how your family can better support you and your caregiver moving forward. If you acknowledge that you're dealing with a devastating disease, your family and friends will want to support you. Don't try to manage caring for someone with AD alone. Families often share stories of frustration and disappointment when they are not told of a loved one's diagnosis. They express feelings of being left out and helpless in knowing what to do. The best way to support the entire family is to involve them in discussions and provide them with information.

Caregiver Comment: I was nervous to ask for help, I did not want to burden my children with caregiving for their Dad. One day my adult son spoke to me, saying he was upset that he was not allowed to help out with his Dad. He said it would be his privilege to help care for his Dad. I realized that I had been denying my son time with his Father. It changed my thinking entirely, after that conversation I reached out to others in the family and received an outpouring of support and help.

What happens as AD progresses?

As dementia progresses in patients, they can experience vulnerability. Behavioral symptoms may result from several factors and can co-occur while fluctuating in frequency and severity. It is critical to understand that the individual living with the disease is at times aware of what is happening to them. They may feel scared, diminished and saddened by their cognitive decline. Finding ways to meet individuals where they are at as they decline is important. Identifying ways to create affirming situations and creative responses to deal with the storm of feelings and emotions at play is very important.

Planning for disease progression with the healthcare team

- As the disease progresses, brain cells deteriorate and function changes. Some days will be good, and others difficult, but each day will be different. If family members know what to expect with each disease stage, they will be prepared when symptoms arise.
- There is a significant distinction between mild, moderate and severe dementia. The Alzheimer's Association has a comprehensive website for caregivers and family members that describes what happens in each stage of disease progression. www.alz.org/alzheimers-dementia/stages
- Predicting and monitoring progression is a team effort and involves talking with the patient, family members and health care providers.
- Behavioral and environmental recommendations can be assembled with your healthcare team. This should include the recommendations of everyone supporting and caring for the patient living with dementia.

- Safety is paramount and knowing when it is appropriate to make life changes is critical. Some of those changes may include:
 - Driving
 - Wandering
 - Cooking
 - Use of electrical appliances
 - Use of tools
 - Managing stairs
- To ensure the wishes of the person living with the disease are honored, advance care planning and discussions are needed on topics such as:
 - Who will be the health care proxy?
 - Who will manage finances?
 - Decisions about living in the home or placement for nursing support
 - End of life decisions

Troubling behaviors and possible contributing factors

One major challenge for caregivers coping with troubling behaviors and personality changes is identifying why they are occurring. Family members should consider:

- Are basic needs causing discomfort for the patient (hunger, thirst, bathroom break (constipation), fatigue, stress, fear)?
- What is the patient's body language saying (pain, discomfort, boredom)?
- How are others reacting to behaviors and could this be causing the patient distress (anger, disapproval, fear)?
- What are the current surroundings the patient is in (unfamiliar, disoriented, over-stimulating, language barriers, new people)?

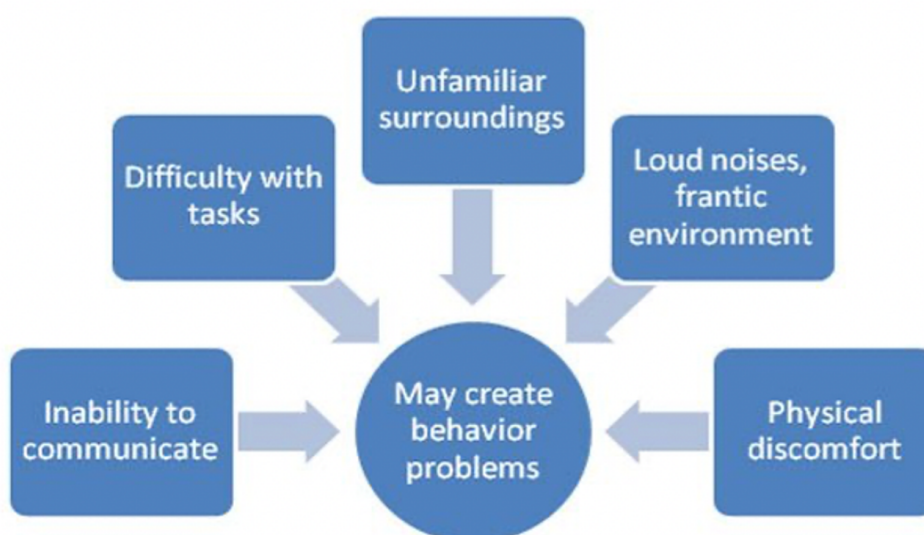


Understanding that behavior changes are symptoms of the disease

It is important to accept that the changes you are seeing in a person with AD, or a related dementia, are associated with brain changes that make a person disagreeable or impulsive. Family members who observe a drastic change should contact their doctor to see if a medical evaluation is needed. While it can be hard to cope with sudden changes to your loved one's personality, it is important to remember the brain's wiring is changed, not the person living with the disease.

Caregiver Comment: I thought my sister was angry with me. She seemed upset and was having outbursts. I avoided her and felt bad. I was not sure what to do to make the situation better. I talked to her doctor and he suggested we see a social worker. I eventually became better informed about the disease and my sister's behaviors. I realized she was having this internal fight in her brain and it had nothing to do with me. I learned how to help her feel calm and loved. I felt so much better and I could see my sister understood I was on her side, even when she was having trouble staying in control.

Common causes of problem behavior



How to cope with troubling behavior

The first step to resolving a troubling behavior is to understand what's triggering the discomfort. Sometimes simple instructions and changes at home, can ease stress and help better manage the symptoms. Ask for help, talk to your health care providers and seek education about AD.

- Identify the triggers that may be causing agitation or an outburst
- Practice redirection and responses to repetitive questions and concerns
- Assure safety and adequate supervision
- Use humor to turn a difficult situation into a less stressful one

- Discover therapies that are supportive and soothing:
 - Reminiscence therapies- looking at photos, listening to music, talking about the past
 - Music therapy – headphones, play lists, devices with music on hand when agitation begins.
 - Aromatherapy – what makes your loved one happy, remind them of soothing smells- cookies baking, sauce on the stove, pine scent (a walk in the woods)
 - Light therapy- warmly lit spots in the home to sit in a comfortable chair
 - Pet therapy- petting a dog or cat, visiting animals, a stuffed animal that is a reminder of a favorite pet
 - Plant therapy- gardening and pulling weeds
 - Massage- hands, feet, back – whatever provides comfort



Tips for Communicating with a person who has dementia

Never

- Argue
- Reason
- Shame
- Lecture
- Say "remember"
- Say "I told you"
- Say "you can't"
- Command/demand
- Condescend
- Force

Instead

- Agree
- Divert
- Distract
- Reassure
- Reminisce
- Repeat/regroup
- Do what they can
- Ask/model
- Encourage
- Reinforce

Person with Alzheimer's:

"I want to go home!"

Caregiver response:

"Tell me about your home"

Person with Alzheimer's:

"What time is it?"

Caregiver response:

"What do you need?"

"How are you feeling?"

Things to consider when interacting with a person who has AD

A patient with dementia may respond to facial expression, tone of voice, and body language. Encourage the use of eye contact, a smile or touch to help convey a message and avoid disagreements.

Agitation and aggression often happen for a reason and identifying contributing factors is important to prevent these behaviors. Look for early signs of agitation or aggression and contact YOUR DOCTOR right away to avoid worsening behaviors.

Caregiver Comment: My Mom was a huge fan of Jeopardy, whenever jeopardy came on she wanted to be in front of the TV. She had been watching the show for years and she would hush you up so she could watch it. When she developed AD she still liked when the show was on, even when her mood was off. I taped several episodes and put them on whenever I noticed she was a little on edge. It just seemed to bring her some joy. I am not sure why it worked but it did.

Tips for supporting someone with dementia

Have a regular routine- coffee or breakfast at the same time, in same room; a car ride; routine walks with dog. Whatever is comfortable and works best should be encouraged and maintained.

Provide a comfortable space- Have a comfortable chair, position it in a soothing space, place items that provide distraction in the general area, provide a cozy blanket, pillow and familiar items nearby.

Promote relaxed interactions-remain calm, flexible, agreeable, use redirection, avoid confrontations and be reassuring.

Create a calm environment- turn off TV, avoid loud noise, avoid poor lighting and surfaces that reflect or may cause shadows. If repair or maintenance work is being done in or outside the home, provide reminders in advance and during the scheduled work time. Consider an outing during a time of significant interruption.

Rummaging and lost items- have a rummaging draw, consider having doubles of items - keep them in the draw, ensure that keys, mail, bills and important papers are not left out on tables and put away, consider a post office box for mail, move trash cans to locations where they can easily be checked for items mistakenly thrown away, consider putting readers, dentures, any medical devices (canes, walkers, etc.) in the same spot and have a back-up when possible.

Develop an activity list- plan exercise, music therapy, activities like folding clothes or watering plants, daily diversions like a car ride, time to sit and recall past events or host visits with family members, grandchildren and old friends.

Dealing with aggression- avoid topics that cause anger, redirect conversations that may escalate, talk calmly and offer encouraging words for concerns being expressed.

Suspicion and paranoia - monitor what is on TV/radio, avoid external contributions to paranoia from outside sources. Violent programs can contribute to paranoia. If hallucinations occur, do not argue about what is real and what is not. Reassure that you're there to provide support and try to move to a new location in the home, reduce fear and provide reassurance.

Reducing restless nights- If sleep/wake cycle is interrupted patients can experience disorientation, confusion at dusk (called sundowning), fear of darkness and general wakefulness. Increase activity during the day, interrupt napping, avoid caffeine and sugar. Keep a calm, quiet comfortable sleep environment. Ensure easy access to bathroom or commode at the bedside. Use a nightlight, allow pets to sleep in the room, offer comfort items. Bright light exposure during the day may help.

Reduce cause for concern- put items that will be difficult to replace if lost -purses/documents- in a safe place. Have back-up glasses and keep in the same place. Encourage one spot for dentures, hearing aids, canes or adaptive equipment- mark the area well for placement reminders. Have mail delivered to a P.O. box and keep paperwork in an area not easily accessed.

Provide protection from harm- keep unsafe substances locked up such as cleaning products, alcohol, firearms, power tools, sharp knives and medication. Block electric outlets, reduce water heater temperatures and put childproof handles on faucets. Consider hiding stove knobs, unplugging microwaves and putting away any sharp objects or items that could be harmful if misused such as a blender or beaters.

Plan for wandering- Monitor for restlessness and encourage activity, install child safety devices in the home to lock doors and windows. Educate your neighbors and local authorities including fire and police about a family member's dementia diagnosis. Encourage use of an ID band or digital GPS tracking device. Keep a recent photo on hand in the event wandering occurs.

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**“Dementia does not rob a person of their dignity.
It’s our reaction to them that does”**

Teepa Snow
Dementia Care Educator

Tips to help with bathing challenges

Helping someone with Alzheimer's disease take a bath or shower can be one of the hardest things you do. To keep the person with Alzheimer's disease safe during bath time, consider the following:

- Never leave the person alone in the tub or shower
- Always check the water temperature
- Use a hand-held showerhead
- Use a rubber bath mat and safety bars
- Use a sturdy shower chair for support to prevent falls if the person is unsteady

Consider the following before starting a bath/shower:

- Getting the soap, washcloth, towels, and shampoo ready
- Make sure the bathroom is warm and well lit
- Play soft music if it helps to relax the person
- Be matter-of-fact about bathing. Say, "It's time for a bath now." Don't argue about the need for a bath or shower
- Be gentle and respectful. Tell the person what you are going to do, step by step
- Make sure the water temperature is comfortable
- Don't use bath oil. It can make the tub slippery and may also cause urinary tract infections.

During a bath or shower, allow the person with Alzheimer's disease to do as much as possible. This protects his/her dignity and helps the person feel more in control. Here are other tips:

- Put a towel over the person's shoulders or lap. This helps him/her feel less exposed. Use a sponge or washcloth to clean under the towel.
- Distract the person by talking about something else if he/she becomes upset.
- Give the person a washcloth to hold. This makes it less likely that he or she will try to hit you.

Suggestions for after bathing:

- Prevent rashes or infections by patting the person's skin with a towel. Make sure the person is completely dry. Be sure to dry between folds of skin.
- If the person is incontinent, use a protective ointment, such as petroleum jelly, around the rectum, vagina, or penis.
- If the person has trouble getting in and out of the bathtub, give a sponge bath instead.

Additional bathing tips:

For most people, a full bath or shower two or three times a week is enough. Between full baths, a sponge bath to clean the face, hands, feet, underarms, and genitals is all you need to do every day. Also:

- Washing the person's hair in the sink with a hose attachment may be easier than doing it in the shower or bathtub.
- Get professional help with bathing if it becomes too hard for you to do on your own

How to handle outbursts and angry behaviors

- Allow the individual some time to be angry alone
- Provide them with some space
- Do not attempt to address behavior while angry
- Do not initiate physical contact while angry
- Ensure they are in a safe space and remove items that could be dangerous
- Attempt to attract the person to a more pleasurable activity if willing
- Contact your doctor to seek help and identify possible medical triggers, get additional assistance and support

Ensure dignity and a sense of caring and belonging

Individuals with dementia are not making a choice to participate in unwelcomed behaviors. It is the disease and the destruction happening in their brain that triggers angry outbursts and unwanted behaviors.

- Provide understanding and encouragement and tell them you care
- Never assign blame and avoid anger at all costs
- Ensure opportunities for positive engagement through activities and redirection whenever possible
- Remember individuals living with AD need to have a sense of purpose and belonging

Caregiver Comment: My wife was taking everything in the house apart, making a mess. She has always been a cleaner and organizer. She did not want anyone to come to our house and refused cleaning support. I was at wits ends and her doctor suggested I join a support group. It was the best thing I ever did. I talked with other family members who encountered the same issues I was facing. Someone in my group suggested I hire a companion to take my wife out for walks, away from the house for a few hours a few days a week. To tell my wife this was a friend coming for an outing. At first my wife was hesitant, but after a walk around our garden with her new companion she left in the car for an ice cream. It has been a wonderful respite for both of us, she loves being social and getting out and I have time to get things done at home.



Advice on wandering

Watch for signs of restlessness which can be an early indication

- Offer reassurance – reinforce that there is nothing to worry about, take a brief walk around the home together and point out that there is nothing out of the ordinary.
- Provide distractions - Examples: enlist their help with a household chores (folding clothes, washing or counting recycling returns for the supermarket), turn on a favorite TV show (family members sometimes use YouTube videos or cellphone video of family/friends)
- Redirect with exercise or an activity – take a walk or a car ride

Plan ahead to prevent or re-direct wandering behavior

- Consider installing child safety devices in your home to keep doors secure.
- Move items like coats, boots and house keys away from the door
- Have a plan in place should wandering occur
- Have a recent photo available
- Ensure that neighbors and local police know someone in your home has dementia
- Consider purchasing an ID bracelet, GPS technology tracking devices, and a laminated card kept in clothing with name, home address and contact number.
- Investigate the Alzheimer's Association's Medic Alert and Safe Return Program

Communication Do's and Don'ts

Do Not:

- Argue, confront, correct
- Give orders, make demands
- Talk down to a person
- Talk about a person in his/her presence
- Ask question that require too many facts
- Try to explain or prepare too far in advance
- Take negative comments personally
- Be insincere when asking questions when you are not offering a choice
- Give too many choices
- Take anything for granted

Do:

- Listen carefully
- Help the person fill in the blanks
- Read facial expressions and body language and try to respond appropriately
- Give compliments
- Ask opinions
- Ask open-ended questions
- Give generous praise
- Use common sense
- Enjoy the person
- Take the blame, apologize
- Be sincere
- Use the person's life story
- Use positive language

Bell & Troxel pp. 115-126

Bob's Last Marathon Podcast: [Understanding Agitation](#)

Resources for caregivers/family members

Educational Resources:

- The DICE approach website at www.diceapproach.com has a caregiving training program that offers education on how to recognize behaviors, understand how they are being triggered and to respond. Understanding what is happening improves communication with patients and providers so the optimal approach to support and treatment is provided.
- The Savvy Caregiver Training is designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with Alzheimer's disease. To learn more about this program, visit: www.mass.gov/news/training-for-families-caring-for-individuals-living-with-dementia
- NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. www.nia.nih.gov/alzheimers
- The Alzheimer's Association provides education and resources for families facing Alzheimer's disease. www.alz.org
- The AARP provides family caregiving Information and resources www.aarp.org/caregiving/answers/info-2017/caregiver-workshops-and-training/
- Road Map to Caregiver Support www.madrc.org/wp-content/uploads/2016/09/Road-Map-to-Caregiving-Guide.pdf

Local Resources

- Massachusetts Councils on Aging <https://mcoaonline.com/>
- PACE (Programs of All Inclusive Care for the Elderly) programs www.mass.gov/program-of-all-inclusive-care-for-the-elderly-pace
- Alzheimers Association, MA/NH www.alz.org/MANH Helpline: 1-800-272-3900
- Alzheimer's Family Support Group of Cape Cod, Support groups, counseling and assistance available, Phone: (508) 896-5170 www.alzheimerscapecod.org
- Hebrew Senior Life—Center for Memory Health caregivers and families www.hebrewseniorlife.org/cmh Phone: (617) 363-8000
- Massachusetts Memory Cafés: social gatherings for people with memory issues or other changes in their thinking and for their family/friends www.memorycafedirectory.com/memory-cafes-in-massachusetts/
- Honoring Choices www.honoringchoicesmass.com/

Mass General Brigham Resources

- Massachusetts General Hospital: Dementia Care Collaborative - Monthly Conversations with Caregivers series and Caregiver Support Groups. (617) 724-0406 <https://dementiacarecollaborative.org>
- Brigham and Women's Hospital: Center for Brain/Mind Medicine (CBBM) - Social workers see patients receiving care at CBMM. Caregiver Dementia Skills and Wellness group educates about dementia-related behavior and coping. www.brighamandwomens.org/neurology/cognitive-and-behavioral-neurology/center-for-brain-mind-medicine

Clinical Support

- MGH Memory Disorders Division: www.massgeneral.org/neurology/treatments-and-services/memory-disorders-division
- MGH Multicultural Assessment and Research Center: www.massgeneral.org/psychiatry/treatments-and-services/multicultural-assessment-and-research-center
- BWH Center for Brain/Mind Medicine: www.madrc.org/bwh-center-for-brain-mind-medicine/
- BWH Rapid Diagnostic Clinic: www.madrc.org/bwh-center-for-brain-mind-medicine//wp-content/uploads/2016/09/RDC-Clinician-Info.pdf
- McLean Memory Diagnostic & Assessment Clinic: www.mcleanhospital.org/older-adult

Research participation is critical to finding a cure!

Massachusetts Alzheimer's Disease Research Center (MADRC), the Center for Alzheimer Research and Treatment (CART) at Brigham and Women's Hospital, and Geriatric Psychiatry Research Program at McLean Hospital offer a variety of research opportunities ranging from observational studies to clinical trials. Several studies are underway to look at the management of NPS. Visit www.MADRC.org, www.BWHCART.org and www.geriatricpsychiatryresearch.org for additional information and resources.

National Institutes of Health: www.NIH.gov

Alzheimer's Association: www.alz.org

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