

Steps to Managing Challenging Symptoms and Behaviors in Dementia

Dementia involves both a decline in thinking and in daily function. Dementia may be caused by a number of different underlying diseases that affect the brain, the most common being Alzheimer's disease. In addition to problems with thinking and function, the majority of patients with dementia will also experience depression, anxiety, decreased motivation, agitation, seeing or hearing things that others cannot, as well as other behavioral changes. These types of symptoms, sometimes referred to as behavioral and psychological symptoms of dementia, can be extremely difficult for patients and their caregivers. Described here are several helpful approaches. Sometimes, medications may be needed to treat these symptoms. Your clinician should discuss with you specifically what medications can and cannot help with and what are the potential side effects to consider.

The 4 Rs: Reassure, Reconsider, Redirect, and Relax

- **Reassure** your loved one that everything is alright, using phrases such as, "You're safe," "Everything is okay," and "I'm here for you." You may need to reassure repeatedly.
 - Because of dementia, familiar people and places may become unfamiliar; environments may be difficult to understand leading to a sense of feeling overwhelmed.
- **Reconsider** your loved one's perspective. For example, a home health aide may seem like a stranger to your loved one despite having met multiple times. This can lead to confusion and anxiety. An inability to carry out what once may have been straightforward tasks can result in frustration and anger.
- **Redirect** your loved one to something they enjoy. Saying "stop" or "no" rarely works and may worsen behaviors. Instead, you may redirect to a different room, offer a beloved item like a family album, or involve them in a comforting activity such as listening to music, engaging with a real or artificial pet, or enjoying a healthy snack.
 - **Communication:** It can be very difficult to do so when your loved one may be yelling and agitated, but maintaining a nurturing, gentle tone and soft volume has a calming effect.
- **Relaxing** and remaining calm will be soothing for your loved one. Even people living with more advanced dementia can pick up on non-verbal cues. It is also critical that you take care of yourself and find time to rest and recharge. Caregiver support groups and the **Alzheimer's Association 24/7 Helpline (800-272-3900)** are excellent resources.

More on Communication (The Three Time Principles)

- **Take your time:** allow sufficient time when talking with your loved one. Try to reduce any distractions in the environment to make it easier for you and your loved one to focus attention.
- **One thing at a time:** as dementia advances, you may need to slow down your speech, simplify your choice of vocabulary, and break down tasks into simple, one-step-at-a-time instructions. For example, when getting dressed you may first instruct to raise one leg, then to raise the other leg, and then to stand up.
- **Offer timely praise:** in dementia, it is best to praise positive behaviors and avoid criticizing difficult behaviors. Positive praise can reinforce healthy behaviors, whereas criticism will most likely trigger agitation.

Managing Memory Problems

- **Don't delay:** write tasks down immediately, take medications when the reminder alarm goes off.
- **Keep it simple:** use one calendar for scheduling, have a designated area where medication tray is located or where the home whiteboard for daily reminders is kept.
- **Make it routine:** use memory aids all the time, every time. Rely on calendars and write out instructions. The more routine something is, the more likely it is to become a habit.
- **Use pictures** instead of words for lists and instructions. Pictures may be easier to remember or understand.
- **Don't fight false memories.** Your loved one may think it is time to go to work or get your child (even though they are an adult now) ready for school. Attempting to correct may cause distress. Gently reassure and redirect to something else.

Wandering

- Your loved one may attempt to wander outside the home. This can be dangerous. They may be remembering things from the past, such as going to work.
- Use visual cues, such as a **STOP sign** placed on doors leading to exits.
- Use sliding locks on the top or bottom of doors, but be sure you can open doors quickly in case of a fire.
- Use an alarm or bell that will alert you if a door is opened.
- Enlist family, friends, and in-home supports to provide supervision.
- Wear identification bracelets with their name, diagnosis, and a contact number in case your loved one becomes lost.
- Some people utilize GPS on smart phones or watches. Some trackers can be easily hooked into the police system so that law enforcement can help.

Repeatedly Following You Around the House (Shadowing)

- Due to problems with memory, your loved one may think you've been gone for hours instead of a few moments.
- They may feel anxious if they do not see you as they cannot recall you have just stepped out for a brief time.
- When you need some time to yourself, enlisting the help of others to spend time with your loved one or redirecting to a comforting and occupying activity may be helpful.
- Your doctor or social worker may be able to refer for **respite care**, a service that can provide nursing care and supervision for several days outside the home.

Illusions and Hallucinations

- Illusions are misperceptions of things that are really there; hallucinations are perceptions of people, animals, or other things that are not really present. Vision and hearing are the two ways in which these most commonly occur in dementia. You may see your loved one interacting with a person, animal, etc., that you cannot see or hear.
- **Vision and hearing correction:** impaired vision and hearing can lead to misperceptions. A good eye and hearing exam is a first step. Your loved one may need corrective lenses, hearing aids, etc.
 - Increase the lighting if there is a distressing visual hallucination associated with a specific environment.
- Some hallucinations may be benign or even comforting. These hallucinations are often best tolerated and may not need any specific interventions. Other types of hallucinations may be disturbing and frightening.
- **Use the 4 Rs (see above):** Reassure with calm, reality-based statements. Remind them they are safe. You may redirect to a healthy snack, going for a walk, looking through family photos. The goal may not be to get rid of hallucinations entirely, but rather to decrease their frequency and how distressing they are.

Depression and Anxiety:

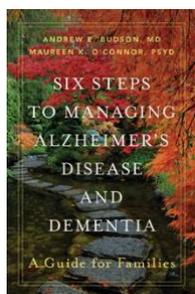
- Both are common in dementia. Those parts of the brain important for memory and thinking are also involved with the regulation of mood.
- Behavioral strategies include aerobic exercise such as walking. Meditation and other relaxing activities may help. Check with your loved one's doctor prior to starting a new exercise program.
- Your loved one's doctor may recommend medications for depression and anxiety. One class of these medications is the selective serotonin reuptake inhibitors, or SSRIs.

Apathy (diminished motivation) and Resistance (stubbornness):

- Your loved one may be content sitting in their chair for hours, but at other moments make rash choices that place them or others at risk.
- For apathy, routine is key. Encourage getting out of bed at a normal time and occupying the day with scheduled activities (adult day programs, home activities, exercise, meals).
- When it comes time to engage in an activity, such as dressing or hygiene, they may become resistant. Remember the 4Rs and Three Time Principles.

Aggressiveness, Agitation, and Disinhibition

- Use those 4Rs and Three Time Principles. Consider calming music, soothing aromas, and a less stimulating environment.
- Identify triggers for aggression and agitation so as to avoid or plan different approaches.
- Medical problems, for example infections, can cause increased agitation and confusion. If you are worried about a new medical issue, please consider seeking medical attention for your loved one.
- **Sundowning:** thinking, memory, and behaviors worsen later in the day. Avoid overstimulation or stressful activities later in the day.
- Talk to your loved one's doctor about whether certain medications may be needed for managing aggression and agitation.
- **Safety tips:** secure or remove firearms from the home, give away power tools, and potentially place childproof locks on cabinets. If your loved one's safety or the safety of others is at risk, call 911.



This information has been adapted with permission from:

Six Steps to Managing Alzheimer's Disease and Dementia: A Guide for Families, Oxford University Press, by Dr. Andrew E. Budson and Dr. Maureen K. O'Connor.

For more information, please consult your local library, bookstore, or online bookseller.