

Spending Time with Someone with More Advanced Dementia

Many care partners find it difficult to connect with people in more advanced stages, because the person may not verbally respond or behave in the typical, usual, or expected ways. Other changes in the later stages include increased sleeping, difficulty chewing and swallowing, weight loss, vulnerability to infections and skin breakdown, incontinence and decreased mobility. All of these changes may make it difficult to spend time with an individual with more advanced dementia. However, individuals are still able to take in information through their senses, and have a capacity for enjoyment and relaxation. Many individuals will be able to participate in repetitive movements or simple, short tasks such as wiping a surface with a cloth or rolling yarn.

It's important to remember that we all continue to want and need human connection, attention, and affection. People are still people through this entire process.

At each stage of the disease process, it will be necessary to modify activities to match the person's abilities and interests so that the person is able to continue to participate. Engagement and activities should focus on the senses: sight, touch, smell, hearing, and taste. Try to have realistic expectations and don't feel disappointed if the person does not respond in the manner you anticipate. If the person isn't interested or motivated when an activity is offered, ask again later. As the disease progresses, the person may not be able to sustain attention for long, so think about the quality, not the quantity, of the time you spend together.

Sometimes there will be lovely moments when the person's facial expressions – sparkling eyes, a smile or a grip of the hand – will indicate that the person is noticing and responding to our attempts to reach out to them. However, there will be other times when the person doesn't open their eyes or even appears to turn their head or body away from us, which can make us wonder whether we are getting through to the person. It is important to continue to relate to the person as if they are still able to understand what you are saying.

Ways to Connect

- Make eye contact and smile.
Say the person's name.
- Hold hands, give a hand massage, or gently stroke the hands. Some people enjoy oil or lotion scented with essential oils, such as lavender.
- Never assume that the person cannot hear or understand you.
- Reminisce about their past.
Talk about things of interest.
- Make the person physically comfortable according to habits and preferences.
- Place the bed or favorite chair close to a window with a nice view, or escort the person outside and spend time together in nature.
- Place flowering plants in the room.
- Read aloud to the person or look at pictures in a book or photo album.
- Watch birds at the bird feeder or view fish in a tank.
- Smell fresh herbs.
- Watch a favorite movie or musical together.
- Listen to a personalized music playlist of the person's favorite songs.
- Ask the person to wash the fruits and vegetables or fold the napkins for the meal.

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Care Partners Are Affected Too



Dementia not only affects those diagnosed with it; it also impacts all those involved in that person's life. Most resources focus on the care of the person with the disease, but care partners are also significantly affected by the disease and need to be cognizant

of its effects on them so they can take the necessary steps to stay healthy—both physically and emotionally—in order to better care for their loved ones.

It is important, as a care partner, to adjust your expectations in order to find joy in smaller, daily successes. This will help you avoid feeling overwhelmed, frustrated, and disappointed. Despite this, frustration, disappointment, anger, and many other emotions might eventually surface—and quite understandably.

Many people who care for a loved one with dementia experience a roller coaster of emotions. It is sad to watch someone you love change, and it is also sad to see the reactive change in us. We often feel that we can't do enough, and this guilt is only outweighed by the guilt of not wanting to be in the caregiving role in the first place, which pulls at us and creates a terrible game of emotional tug-of-war.

That is when care partners for people with dementia often begin to struggle emotionally. The changes in the person with dementia are gradual, and most don't affect the physical appearance of the person diagnosed, especially early on. Care partners feel guilty about needing a break because they feel like they are letting their loved ones down.

Care partners often burden themselves with a long list of self-imposed faults that are either imagined or unavoidable. These feelings can stem from doing or saying what you believe is the wrong thing, not doing what you think is enough, or not behaving in a manner that you think is right. Guilt exists only in one's mind and is often out of sync with reality and can only hurt you by making you feel bad and draining your energy.

As a care partner, all you can do is your best with the skills and resources at your disposal. Acknowledge that you don't have all the answers, and reach out to others for help.

Ways to Connect *Continued*

- Sing together.
- Expose the person to the scents of freshly baked cookies, bread, or favorite meals, and enjoy the food together.
- Provide fabric of different textures to hold and feel.
- Make a rhythmic noise together on the table using a stick, spoon, rain stick, or instrument, with or without music.
- Use an essential oil diffuser in the room or provide aromatherapy.
- Depending on their mobility, the person with dementia may connect through dancing or movement to music. Encourage or assist the individual with arm and leg movements as needed.
- Give the person a paint brush to hold or use for painting, or a pencil and paper for drawing.
- Provide a stuffed animal, cuddly toy or doll.
- Enjoy ice cream or a favorite drink together.
- Pressing: press glued paper down so it stays in place (for example, in a collage).
- Create art with a rubber stamp.
- Fold dish towels, clothes, bed linens, or paper.
- Participate in familiar spiritual or religious practices.
- Spend time petting a dog or cat.
- Just be present. Sit with the person and respond to any motions or noises the person makes.

Self-Care Suggestions

- Accept your need to grieve and feel your loss before and after the person dies.
- Take breaks from caring for the person. Find someone you trust to spend time with your loved one while you get some rest.
- Don't assume people know what you need. Let family and friends know how they can help. Provide specific requests such as cooked meals, running errands, or visiting with the person, so you can have a break.
- Eat well, exercise, and get lots of rest.
- Share your feelings with people you trust who are good listeners.
- Consider joining a support group or seek professional help if your feelings become overwhelming.
- Get regular check-ups from your health care provider.
- Meditate or practice deep breathing.
- Do something that feeds your soul every day.
- Spend time with your friends.
- Recognize your importance and value as a person.

Resources for Care Assistance

During the course of the disease, you will probably have to engage with a wide range of services. These range from in-home care to a shared residential care setting. Following are a few different options.

Personal Companions. These paid or unpaid helpers are companions or friends. A neighbor might fill this role, or you may hire someone through a home care agency. This person should engage the person with dementia in things he or she likes to do. Visits should be a source of stimulation for the person with dementia.

Home Health Aides. These paid staff are companions and personal care aides. The person should be trained in providing hands-on personal care, such as bathing, dressing, and assistance in the bathroom. This staff can be hired through an agency or hired privately.

Social Model Day Programs. These are day programs that offer social activities and meals. They are a great resource for people to engage with others in the same cognitive situation in an environment where they will not feel judged. Many people with dementia enjoy going and often make new friends.

Medical Model Day Programs. These programs offer the same benefits of the social model day program but also provide personal care, medications, and other medical needs. Since a person may need to qualify for this program, it is good to call ahead and ask what would be required.

Assisted Living. This residence provides meals, social activities, and different levels of support or care

depending on the organization. An assessment is conducted prior to moving in to determine the care needs of the individual. No all assisted living communities can support people with dementia.

Memory Care Assisted Living. This residence provides a higher level of care than assisted living does. In most programs, there are fewer residents assigned to staff so that staff can help residents with all their needs. Often, the program space for memory care is secure so that residents cannot leave the care community unattended.

Nursing Home Care. This residence provides a higher level of care than memory care or assisted living communities do. They focus on medical needs.

Rehabilitation. This setting helps to care for people who need rehabilitation services such as physical or occupational therapy. These are usually short-term services after surgery, an acute illness, or broken bones.

Palliative Care. This is intended to provide relief from symptoms and discomfort that can accompany late stage dementia and is appropriate for people in all stages of a disease. A person needs to qualify to receive services.

Hospice Care. This is intended to make sure that people who are not expected to live more than six months are offered all services to make them comfortable. A person needs to qualify for these services. For many families, hospice has provided an extra layer of support for families, additional attention to the person with dementia, and help in coordinating all areas of care.