

# living with alzheimer's

for caregivers



tips for late-stage caregivers



## tip 1: remember that the “self” of the person is not lost

Many times, people talk about Alzheimer’s disease or other dementias as taking away the person’s “**self**.” This is not actually what happens. The “self” contains those aspects of a person that make him or her unique. Although persons in the late stage of dementia typically lose their ability to talk about themselves and their needs, research tells us that some core of the person’s self may remain throughout the course of the disease. What this means for family members is that you may continue to connect with the person throughout the late stage of the disease, and that it helps everyone when family attempt to connect in those ways.

**Please list below some of the unique characteristics of the person with Alzheimer’s disease.**

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**What signs of those characteristics can you see now in that person?**

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## tip 2: connect with the “self” through the senses

Because the world is primarily experienced in the late stages through touch, sound, sight, taste and smell, providing enjoyable **sensory experiences** for the person can be a powerful way to express your caring. A favorite flavor, the scent of a familiar flower or a soft touch can soothe, calm and communicate a caring presence.

**Check the ways below that you have been able to connect with the person’s self through the senses:**

- ☐ Playing favorite music
- ☐ Reading portions of books that have held meaning for the person
- ☐ Looking at old photos together
- ☐ Preparing the person’s favorite foods
- ☐ Rubbing lotion with a favorite scent into the skin
- ☐ Brushing the person’s hair
- ☐ Holding hands
- ☐ Bringing scented flowers for him or her to smell
- ☐ Sitting outside together in the sunshine

**What other ways to connect through the senses could you try?**

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## tip 3: involve the person you care for in providing hands-on care

In the late stages of the disease, activities of daily living increasingly involve caregiving provided by family members. It is challenging but very important to find ways to involve the person with Alzheimer's disease in his or her own care. Not only does this preserve the person's sense of self, but it also reduces resistance to the care being provided. The person with dementia may be unable to verbally communicate or provide all of his or her own care at the end of the late stage, but there are ways to include the person in the process.

When feeding, for example, you may:

- Guide his or her hand with your hand
- Sit across from the person while eating so he or she can mimic you

When dressing, you may:

- Talk the process through while providing assistance with pulling on clothing

When washing up, you may:

- Use a hand-over-hand technique to help with washing with a facecloth
- Have the person imitate your motions as you brush your own teeth

**Ways to involve the person in their care that are already in place include:**

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**Other ideas to try:**

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## tip 4: monitor eating

One of the most important daily caregiving tasks is monitoring eating. It can be very difficult to see someone unable to eat as he or she would have enjoyed at an earlier time. The person with the disease may forget to eat and/or lose his or her appetite, and the sense of taste diminishes. Adding sugar to food may encourage eating. The physician may even suggest supplements between meals to add calories. Because sense of thirst diminishes as well, it is important to encourage the person to drink liquids or to eat high liquid foods such as watermelon, peaches, pears or sherbet.

To help someone in the late stage stay nourished, plan to allow plenty of time for eating. Make sure the person is in a comfortable, upright position. Choose soft foods that can be chewed and swallowed easily, and make liquids easier to swallow by adding cornstarch or unflavored gelatin to water, juice, milk, broth and soup. Learn the Heimlich maneuver to be prepared for possible choking, and monitor weight loss. See the doctor to have weight loss evaluated if you notice drastic changes.

**Check the tips below that you are already doing and that work for you now, and Remember that these will change over time, so stay flexible!**

- ☐ Offer plenty of liquids and high liquid foods
- ☐ Allow lots of time for eating
- ☐ Choose soft foods
- ☐ Add bulk to liquids
- ☐ Add sugar if it encourages eating
- ☐ Watch for possible signs of choking
- ☐ Learn the Heimlich maneuver
- ☐ Monitor weight and report weight loss to doctors

**Other suggestions include:**

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# tip 5: plan for toileting

Difficulties with toileting are very common in the late stage of Alzheimer’s disease. The person will need increasing levels of assistance with toileting as the disease progresses. For example, beginning in the middle stage, the individual may not know where to dispose of used toilet paper and may need guidance with this. By the late stage, some family members walk the person to the bathroom for each visit and guide the person through the process, providing cues for the steps and helping where necessary. As the person continues to progress in the late stage, incontinence often becomes an issue that continues until the end of life.

**Check the tips below that you currently use to assist with toileting for the person with Alzheimer’s.**

- ☐ Set a toileting schedule.
- ☐ Use incontinence products.
- ☐ Monitor bowel movements.
- ☐ Identify when accidents occur and plan accordingly.
- ☐ Be sure that the person consumes ample fluids
- ☐ Provide visual cues to find the bathroom,
- ☐ Keep the bathroom door open.
- ☐ Provide reminders to use the bathroom.

**Other things we do to help with toileting include:**

**Other suggestions to try:**

## tip 6: monitor general health

As the person you care for becomes less able to communicate their discomfort verbally, it becomes increasingly important to monitor general health issues and watch for behaviors that could signal a problem. When in doubt about whether to contact the doctor, err on the side of caution, and let the office know about the symptoms that the person with Alzheimer's disease is experiencing. Many of these symptoms can indicate something that is important to treat promptly with medication.

### Watch for and report the following:

- ☐ Coughing
- ☐ Excessive thirst or sudden weight loss
- ☐ Sudden bowel and bladder changes
- ☐ Weakness
- ☐ Fever
- ☐ Painful or more frequent urination
- ☐ Open sores
- ☐ Hallucinations, delusions, agitation or aggression not previously seen
- ☐ Changes in the ability to move, sleep or breathe
- ☐ Signs of pain, including bruises, swelling, fever, vomiting, uneven skin tone and facial expressions or sounds related to distress.

### Other symptoms to watch for:

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**Tips for keeping the person healthy:**

- ☐ Keep the person mobile by helping him or her to move every couple of hours.
- ☐ Learn how to lift the person to avoid injury to the person or yourself. Be sure to never lift the person by pulling on his or her arms or shoulders as this could cause injury. If you are unsure how to lift the person, consult with one of his or her care providers, such as a physical therapist or nurse.
- ☐ Use pillows or pads to protect bony areas such as elbows, knees and hips to reduce the risk of bed sores. Apply moisturizer gently over bony areas.
- ☐ Keep the teeth and mouth clean. This reduces the risk of bacteria in the mouth that can lead to infection. Brush the person's teeth at least twice a day.
- ☐ Treat cuts and scrapes immediately. Clean cuts with warm soapy water and apply an antibiotic ointment. If the cut is deep, seek professional medical help.
- ☐ Do all that you can to prevent flu and pneumonia. The flu (influenza) can lead to pneumonia (infection in the lungs). It's vital for the person as well as the caregiver and/or family members who spend time with the person to get flu vaccines every year to help reduce risk.

**Other suggestions include:**

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## tip 7: get assistance when care needs exceed your limits

As the disease progresses, care needs arise that could not have been foreseen, some of which require physical strength or availability that you could never provide without considerable assistance. Sometimes, medical needs arise that require intervention by trained professionals or paraprofessionals.

**Some indications that additional help is needed are listed below. Please check those that apply to your situation now, and consider these as indicators for the need to get additional assistance with care.**

- ☐ Increase in the health care needs of the person, including the need for medical equipment requiring trained providers
- ☐ Change in the health of the caregiving family members
- ☐ Hands-on care requiring skill or strength beyond what the caregivers can provide
- ☐ Safety issues and/or behavioral issues that could not be resolved by a different approach or medication change, making home care no longer possible
- ☐ More comfort knowing that the person would be well cared for by those with medical training.

For these reasons, among others, the decision may need to be made to get more assistance with providing care for the person with Alzheimer's. This may mean bringing care into the home, which involves hiring, monitoring and paying for care. These issues are covered in our Living with Alzheimer's for Caregivers Middle-Stage program. In the late stages, however, care needs may exceed what can be provided at home even with paid assistance, and is often provided most professionally and cost-effectively by a facility. This can mean moving the person you are caring for at some point in order for him or her to get the care that is needed.

Many times, advance planning has been made that involves being cared for in a facility, and the choice of moving into long-term care is relatively easy. Sometimes, though, it can be a difficult decision to engage a facility for care provision, particularly when a promise had been made not to do that. Remember that a promise made at an earlier time not to consider placement for the person is more about continuing to give the

person what he or she needs than about where that care takes place. In addition, most family members feel some degree of guilt regardless of how they decide to proceed. There are many good ways to provide quality care. Which choice to make are among the most difficult decisions that families face. But families who have been through the process tell us that it is best to gather information, make a decision and move forward rather than trying to second-guess your decision after the fact.

It's best to begin visiting facilities before needing an immediate placement. Visit a few, and try to involve those closest to the person in the decision making. A meeting, whether in person or via teleconference, will help placement go more smoothly. As with arranging care in the home, it's helpful to have a neutral person run these meetings. The goal is to give everyone involved the opportunity to express their thoughts. Care consultation services can be helpful for families making a decision about nursing home placement.

**Other points to consider:**

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**Notes:**

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## tip 8: make plans in advance to facilitate a move

When moving someone with dementia to a care facility, there is no substitute for advance planning. It's best to begin visiting facilities before needing an immediate placement to avoid needing to make a decision quickly and under stressful circumstances. Be sure to be looking for a facility that is dedicated to connecting with the person's sense of self through individualized care planning.

Research the choices available in the area first. This can easily be done by using the Alzheimer's Association's Community Resource Finder, available through the website at [www.alz.org](http://www.alz.org), or by calling the Helpline at 1-800-272-3900. Visit a few, and try to involve those closest to the person in the decision making. A meeting, whether in person or via teleconference, will help placement go more smoothly.

Sameness, routine and predictability are very helpful to someone with Alzheimer's disease or a related dementia and allow the person to function at the highest level possible. Moves can be difficult for the person, but there are ways of easing the transition.

When facilitating a move, there are many questions to consider. What do I tell the person with Alzheimer's? How can I make it easier for us all? Here are some tips:

- ❑ Keep it brief and simple. Long explanations or trying to convince the person only increases resistance. It is usually best to tell the person only a few days in advance of the move.
- ❑ Acknowledge feelings. Anger and/or sadness are normal reactions to anticipation of a move and loss of independence. If the person expresses sadness and/or cries, join them in sorrow; allow your own tears and give the person a hug. You may not need to do anything else.
- ❑ Team up with family, friends, and/or professionals. You can team up with a sibling, spouse, other relative, friend or more than one person to make the move. It may be too stressful to try to do yourself.
- ❑ Talk to staff beforehand and tell them about the person with dementia.
- ❑ On the day of the move, bring the person at a time that works best with the person's habits and comfort level.

- ❑ Stay awhile to help the person orient and get settled.
- ❑ Seek counseling if needed. Sometimes the challenges of caregiving trigger old feelings that we thought were dealt with long ago. If you have a resurgence of long-standing unresolved feelings of sadness, guilt or anger, it's helpful to seek counseling with a qualified mental health professional to help you work through this difficult transition.
- ❑ Make plans ahead for how to spend your days when the person in your family has made the move into long-term care. Consider the fact that you may experience fatigue now that you are no longer called on to provide care in the same way that you had been. Think about your need for self-care, and build in time dedicated to your needs and interests.

**Other suggestions include:**

[illegible]

## tip 9: consider using hospice and palliative care services

**Hospice** is a unique option for managing care because it brings care to the person. In this way, visits to the doctor and trips to the hospital are minimized. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families. Hospice places an emphasis on maximizing patient comfort and providing counseling and bereavement services to the family before and after the person dies. To qualify for hospice benefits under Medicare, a physician must diagnosis the person with Alzheimer's disease as having less than six months to live.

While hospice care is designed to provide care in the last six months of life, **palliative care** can be provided throughout the late stage. Hospice care includes palliative care, which seeks to address not only physical pain but also emotional, social and spiritual pain to achieve the best possible quality of life for patients and their families. However, its focus is not to cure a disease. Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness. Health care professionals who specialize in hospice and palliative care work closely with staff, volunteers and family members to address all of the symptoms of illness, with the aim of promoting comfort and dignity.

*Myth: Bringing in hospice means giving up on the person.*

**Reality: Hospice provides care and comfort for the entire family to help with the end of life once it is inevitable.**

While hospice care is provided at the end of life, it by no means signifies that you or anyone else has given up on the person with Alzheimer's disease. Giving up implies that less care is provided because there is no hope. On the contrary, when hospice is brought in, *more* care is provided because a care plan is developed that focuses on many aspects of the person's well-being in addition to treating symptoms, such as emotional care, comfort, pain management, spiritual care and support for family members and friends close to the person with the disease.

*Myth: Hospice will leave the person I care for drugged and unable to function.*

**Reality: Hospice will provide the care that the person needs to manage pain. Palliative care offers an alternative to pain or suffering without shortening life.**

Hospice agencies and their staff members have specialized knowledge about end-of-life care, including pain management. While it is commonly assumed that all pain medications induce heavy sedation and increased tolerance, there is no empirically-based evidence suggesting that pain medications such as opioids lead to addiction. With proper administration, pain medications can provide comfort and relief while still allowing the person to function normally

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## tip 10: plan for the end of life

It is possible to have a positive end-of-life experience with someone with dementia, and it involves connecting with the person in a different way than ever before – connecting with the person's humanness and the essence of who the person continues to be —the “self” of that person. Some may think of it as a spiritual connection at this point, and it can be a very meaningful way of connecting with someone and his or her core being.

It is crucial to respect the end-of-life wishes previously expressed by the person with dementia. The best way to do this is by ensuring that **advance directives** are already in place. If it was not possible, some decisions about level and type of care may need to be made in the moment based on an understanding of the person's wishes as he or she stated them in the past in combination with the person's current medical situation. As a general principle, maintaining **comfort** and **connection** for the person with dementia should be paramount.

When a person with Alzheimer's disease dies, it is normal to feel a familiar yet new kind of loss, considering that family members often experience anticipatory grief while the person is still alive. It is also normal and very common to feel relief that the person's struggles, as well as yours, have ended. You are entitled to all of your emotions and may start feeling them in different ways or varying intensities at the end of the person's life. As this happens, you may mourn him or her and experience feelings such as denial, anger, sadness and acceptance. These feelings are difficult, but they are normal. Everyone grieves differently and at his or her own pace.

Regardless of whether you are able to have an optimal end-of-life experience with the person, there are ways to honor the person's spirit at or after the end of life. A spiritual advisor through a place of worship, a bereavement counselor or a valued friend or family member can be a source of support to help you find a way to honor your relationship and your memories of the person.

**Symptoms of grief** include periods of helplessness, despair and depression; changes in appetite or sleep patterns; feelings of anger or frustration; and withdrawal from social activities and relationships. You may experience unresolved grief because you are



not able to express how you feel and create a sense of closure. You might feel as though you can't say goodbye. If your grief is so intense that you feel your well-being is at risk, do not hesitate to ask for help from your doctor or a professional counselor. In addition, a caregiver support group through your chapter, the Online Community and the Alzheimer's Association's Helpline are all able to provide support from others who have juggled the mix of feelings that family members experience at this time. They are all ready to help and are happy to have you reach out to them.

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