

Early-Stage Caregiving

In the early stage of Alzheimer's, most people function independently. He or she may still drive, take part in social activities, volunteer and even work. Your role as care partner is an important one: to provide support and companionship, and help plan for the future.

"Early stage" refers to people, irrespective of age, who are diagnosed with Alzheimer's disease or a related disorder, and are in the beginning stage of the disease. The early stage of Alzheimer's can last for years. A diagnosis of early stage Alzheimer's disease doesn't just affect those with the disease; it affects everyone who loves and cares about them. Learn more about the [stages of Alzheimer's](#).

Your role as care partner

As a care partner (a term many choose to use rather than "caregiver," since a person in the early stage of dementia may not need much assistance), you may find yourself in a new and unfamiliar role. You may be unsure of where to go for information, anxious about what to expect as the disease progresses and concerned about your ability to support the person living with dementia.

These questions and feelings are normal.

With an early diagnosis, you and the person with dementia now have the opportunity to make decisions about the future together, [including legal, financial, and long-term care planning](#). The person living with dementia can take advantage of [available](#)

treatments or participation in clinical trials and you both can benefit from local resources and support services. Being able to take advantage of all these benefits can reduce anxiety about the unknown and lead to better outcomes for everyone involved.

Secondary care partners

The role of a care partner is not limited to spouses, partners or close family members. Care partners may include "families of choice" such as friends, neighbors or long-distance relatives. If you are providing support as a secondary or remote care partner, it may be difficult to determine the exact level of assistance needed without direct observation. Whenever possible, try to connect with others in the support network to share insights or make plans to meet the person with dementia in their own environment.

Finding a new balance

One of the greatest challenges care partners face is not knowing how much assistance to give or when to give it because the person with early-stage dementia is primarily independent with dressing, bathing, walking and may still drive, volunteer or work. The most difficult tasks may involve managing a daily schedule or household budget.

As a care partner, your support with these everyday tasks can help the person with dementia develop new coping strategies that will help to maximize his or her independence. Every relationship is different, but finding balance between interdependence and independence may increase confidence for both of you.

To help you determine when and how to provide the most appropriate support to a person living in the early stage of dementia consider these tips used by other care partners:

- **Safety first:** Is there an immediate safety risk for the person with dementia to perform this task alone? If there is no immediate risk of injury or harm, provide encouragement and continue to provide supervision as necessary.

- **Avoid stress:** Prioritize tasks or actions that do not cause unnecessary stress for the person with dementia. For example, if you know that grocery shopping will be frustrating for the person with dementia, ask for their participation to outline a weekly menu and organize a grocery list.
- **Make a positive assumption:** Assume that the person with dementia is capable of completing the task. If you sense frustration, try to identify the cause of the frustration before intervening. Focus on his or her current needs, rather than dwelling on the future.
- **Create a help signal:** Identify a cue or phrase that you can use to confirm if the person with dementia is comfortable receiving support. For example, you may agree to use a phrase like, "Is there anything I can do to help?" or a nod to signal that it's ok to chime in if the person with dementia is having difficulty remembering a word or name.
- **Talk it over:** The best way to determine how and when to provide support is to ask directly. Ask the person with dementia what they need or the frustrations they may be experiencing. Talk about it, then make a plan.
- **Work better together:** Find activities to do together and keep the conversation going about expectations for how you will provide support. Check in regularly by asking the person with dementia if you are providing a level of assistance that is comfortable or adequate.

Maximizing independence

Free e-Learning course

This program, "Living with Alzheimer's: For Caregivers: Early Stage," provides practical answers to questions that arise in the early stages of Alzheimer's.

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While every person experiences the early stage of dementia differently, it is common that a person in the early-stage may need cues and reminders to help with memory. As a care partner, it may be necessary for you to take the initiative to determine how you may be able to help. For example, he or she may need help with:

- Keeping appointments
- Remembering words or names
- Recalling familiar places or people
- Managing money
- Keeping track of medications
- Planning or organizing
- Transportation

Focus on the person's strengths and how they can remain as independent as possible, and establish a strong channel of communication. Consider ways to work together as a team. For example, if they are still comfortable balancing a checkbook, you may offer to provide a final review.

Understanding emotions

Providing support to a person living with Alzheimer's disease or a related dementia is an ongoing and sometimes emotional process. As care partner, you may be feeling overwhelmed by emotions that range from fear to hope. Emotions may be triggered by thoughts about how this diagnosis will impact your life, but also the anticipation of future challenges. Learning to recognize your emotions may help you move forward

and help the person with dementia live the best life possible.

Emotions you may experience as a care partner

- *I wasted a lot of valuable time denying that this could be possible, when I could have been getting support to help me cope with the diagnosis.*

Sarah H., Care Partner

Denial. The diagnosis may seem unbelievable or difficult to accept. Short-term denial can be a healthy coping mechanism that provides time to adjust, but staying in denial too long can prevent you and the person with the disease from making important decisions about the future. It also can delay his or her ability to live a quality life. If you are experiencing denial about the diagnosis, your ability to help the person with dementia will be hampered until you can come to terms with the diagnosis yourself.

- **Fear.** Fears about the progression of the disease and the challenges in providing future care can be overwhelming and can prevent you from focusing on the present.
- **Stress/Anxiety.** Uncertainty about what to expect as the disease progresses and how to support the person with the diagnosis can lead to increased stress.
- **Anger/Frustration.** Anger towards the diagnosis is a common response to feeling a loss of control over the future. You may be feeling resentment about how your role as a care partner will impact your life.
- **Grief/Depression.** Sadness or a sense of loss over your relationship may also lead to feelings of hopelessness. [Learn more about symptoms of depression.](#)

Emotions the person with dementia may experience

Emotions such as fear and denial are common for both care partners and individuals living in the early stage of the disease. Being able to talk about these emotions together may help you both work past the difficult feelings and spend more time enjoying the present.

You can help the person with dementia to work through feelings of denial and fear about the disease by:

- Encouraging the person to share his or her feelings in a journal
- Spending time doing activities that are meaningful for both of you
- Attending an Alzheimer's Association early-stage support group designed for both the person with dementia and care partner
- Talking to each other about your expectations, questions and concerns

Helping the person with dementia live well

People with Alzheimer's want to live well for as long as possible. The ability to remain healthy, active, engaged and independent are consistent desires identified by newly diagnosed individuals. Care partners play an important role in helping the person with dementia achieve these goals.

Consider the tips below to help the person in early stage stay healthy for as long as possible:

- **Encourage physical activities.** Based on results of some studies, exercise or regular physical activity may play a role in living better with the disease. Choose activities you both enjoy.
- **Prepare meals that maintain a balanced diet** and are low in fat and high in vegetables.

- **Create a daily routine** which promotes quality sleep and engagement with others.
- **Identify situations which may be too stressful** for the person with dementia.
- **Work together** to find what helps the person relax.

Taking care of yourself

Being involved in activities that enhance your sense of well-being may help reduce your stress level. Spend time with friends and family, eat well, engage in physical activity and see the doctor regularly.

Here are tips on how to maintain your own health:

- **Think about ways you can get support now.** For example, include an afternoon to yourself in your monthly schedule. Ask others to visit or go to lunch with the person living with dementia while you're away.
- **Build a support network.** Creating a support system before you think you need it will minimize your stress as the disease progresses. Look at current support systems you have already in place and consider the people you turn to most often in times of need.
- **Connect with other care partners** to acquire encouragement and comfort from others who understand what you're going through. Learn more about [in-person and online support groups](#).
- **Ask for and accept help.** Care partners often wait too long before asking for help from others.
- **Rest when needed** and allow time for yourself and your own interests.
- **Try not to take things personally;** symptoms of the disease can cause an individual to forget events or commitments. Remember this is not a reflection of his or her character.

- **Stay healthy** through diet, exercise and regular visits to the doctor.
- **Stay engaged** by continuing to be involved in activities that are important to you and enhance your sense of wellbeing.
- **Allow yourself** the opportunity to laugh when funny situations arise.

Learn more: [Care Partner Support Groups](#), [Changing Roles in Relationships](#), [Online Community](#)

Getting empowered with information and resources

The more you educate yourself about the disease the more confident and prepared you may feel about the future and your ability to solve problems as the disease progresses. Knowing what to expect and putting plans in place can be empowering for you and the person with dementia.

- **Accepting the diagnosis.**

As a care partner, you may accept the diagnosis before the individual living with the disease. While the individual living with dementia is the only person who can change how he or she feels about the diagnosis, you can share information and provide support to help with the process of acceptance.

Learn more: [Accepting the Diagnosis](#), [Sharing Your Diagnosis](#)

- **Understanding Alzheimer's.**

The symptoms of Alzheimer's usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. While the progression of Alzheimer's disease can differ from person to person, it's normal for a newly diagnosed person to want to compare his or her symptoms with others.

Learn more: [What Is Alzheimer's? 10 Signs, Stages](#)

- **Information on treatments and trials.**

Treatments are available to help with symptoms of the disease. Combining treatment for symptoms with supportive services can help the person live a

quality life for as long as possible. While these treatments address the symptoms of the disease, currently, there is no way to prevent, cure or stop the progression.

Many clinical trials are underway to find effective ways to treat and ultimately cure Alzheimer's. At least 50,000 volunteers are currently needed. [Alzheimer's Association TrialMatch[®]](#), a free, easy-to-use clinical studies matching service.

Learn more: [Current Treatments](#), [Participating in clinical trials](#)

- **Planning for the future.**

People in the early stage of the disease want to have a say in the decisions that will affect their life, including legal, financial and long term care planning. While these conversations can be difficult, including the person in the early stage of the disease in this process can be empowering for everyone involved. As their care partner, knowing the wishes of the individual can help you feel confident about the future decisions you will need to make on their behalf. The sooner plans for the future are established, the better prepared you and the person with dementia will be.

Learn more: [Planning Ahead](#), [Safety](#), [Financial and Legal Resources](#)

- **Living alone.**

With support and resources, many people in the early stage of Alzheimer's live independently. If you are a family member or care partner for someone who lives on his or her own, stay involved. Call or visit often, and make sure the person gets the assistance needed, such as help with housekeeping, meals, transportation, bill paying and other daily chores. Put home safety measures in place, and be aware of any changes that would indicate the need for additional supervision or care.