

living with alzheimer's

for caregivers



tips for early-stage caregivers

tip 1: report early signs and changes

Families may notice a variety of symptoms in the early stage. The hallmark of Alzheimer's disease is memory loss, but not every symptom will affect each person with the disease at the same time or in the same way. Even after the diagnosis has been made, make note of any changes you see in the following areas, and discuss those changes with the doctor. Sometimes those issues may be treatable, and sometimes they can indicate an issue that must be addressed immediately.

Mark any of the early signs of a problem that you notice now by checking the boxes below. These may indicate a shift that could signal a problem in another area.

- ☐ Memory changes
- ☐ Changes in executive functioning
- ☐ Concentration changes
- ☐ Difficulty with reasoning and abstract thinking
- ☐ Difficulty with language and ability to communicate
- ☐ Impaired judgment
- ☐ Confusion with time or place
- ☐ Difficulty with visual-spatial relations
- ☐ Withdrawal from work or social activities
- ☐ Personality changes

Other changes to discuss:

tip 2: stay organized

Symptoms in early-stage Alzheimer's are often more manageable when family members provide some degree of help and encourage the person with the disease to continue living as independently as possible. Notes and shared calendars can be used as a reminder system as well as a way to stay organized. We encourage you to find other creative ways to help the person you care for stay organized by tapping into his or her strengths and abilities. This will allow the person with Alzheimer's disease to cultivate independence as much as possible.

Check the tips below that you are already doing and that work for you now, and add any of your own. Remember that these will change over time, so stay flexible!

- ☐ Notes for the person with Alzheimer's
- ☐ Shared calendars
- ☐ Medication schedules
- ☐ Written "to do" lists
- ☐ Planned times for exercise
- ☐ Written meal plans

Other suggestions include:

tip 4: nurture your relationship

Nurturing your connection with the person with Alzheimer’s disease can sometimes seem to take a back seat to the business of daily life. But keeping your connection foremost in your mind can help everyone enjoy themselves together.

Check the tips below that you currently use to nurture your relationship with the person with Alzheimer’s.

- ☐ Stay flexible with plans. If it’s not a good day, it’s ok to modify or cancel plans.
- ☐ Trust that these ups and downs are normal.
- ☐ Live in and enjoy the present moment together.
- ☐ Gently share your feelings in non-threatening ways.
- ☐ Listen without judging.
- ☐ Reassure the person that you are there as source of support and care.
- ☐ Think of ways to complete tasks as a team,
- ☐ Solve problems together.
- ☐ Experience moments together that help you relate in new ways.
- ☐ Go with the flow .
- ☐ If there is something that you have always wanted to do together, do it now!

Other suggestions include:

tip 5: partner with your medical team

Your care team is made up of those in the health care professions. The physician who made the diagnosis and those in that office – nurses, social workers, nurse practitioners, etc. – are crucial members of your health care team. Building a relationship with the physician takes time and effort, but it can significantly improve the care received by the person with the disease.

Check the tips below that you currently use to partner with the medical team.

- ☐ Make a list of questions for the doctor as they arise and bring it with you to the next appointment.
- ☐ Be sure you also have a notepad on which to record the doctor's responses.
- ☐ Bring a list of everything the person with dementia is taking, including prescription medications, over-the-counter products, and vitamins and supplements.
- ☐ Be open and honest with the doctor, especially if you do not understand something the doctor is saying. Ask for clarification until you understand.
- ☐ Clarify the purpose and results of any tests performed.
- ☐ Determine under what circumstances you can contact the doctor between appointments and what the regular appointment schedule will be.

Other suggestions include:

tip 6: disclose the diagnosis directly

Disclosing a diagnosis of Alzheimer’s disease is a difficult thing to do, as Alzheimer’s is a disease that currently has no cure. Many people think of it as a disease that immediately leaves the person with Alzheimer’s bedbound and unable to do much for him or herself. This stigma is significantly reduced when the disease is brought into the open in the early stages, and this openness allows families to get the support that they need from others.

Most people find that telling people in a matter-of-fact way works best. It allows you and the person with dementia to get the support you need and to serve as advocates for yourselves and others with the disease.

Check the tips below that you are already doing and that work for you now, and add any of your own.

- ☐ Alzheimer’s is not a normal part of aging but a disease of the brain that results in impaired memory, thinking, and behavior.
- ☐ The disease is a medical condition and not a psychological or emotional disorder.
- ☐ The disease does not immediately take all the strengths and abilities away from the person.
- ☐ You and the person with dementia value friendship and want to continue enjoying the company of family and friends throughout the course of the disease.

Other suggestions include:

tip 7: plan now for future care

A diagnosis of Alzheimer's disease presents a factor to include when making future plans. This begins with thinking and talking about what the person with dementia's wishes are for how he or she would prefer care to be provided. The answers to the questions below will dictate what kinds of plans will need to be made in advance, which avoids putting undue demands on friends and family later.

Check the questions below that have already answered or are in the process of being discussed, and add any of your own that you feel are important.

- ☐ Who would the person want to make decisions when he or she no longer can?
- ☐ Where would the person want to live if he or she could no longer be cared for at home?
- ☐ What kinds of medical care does the person want or not want?
- ☐ What transportation is available for when driving is no longer an option?
- ☐ What are his or her preferences about end-of-life decisions?

Other questions might include:

tip 8: take care of financial matters

In the early stage of the disease, it is important for both of you to consider all of the financial situations you will face. You may choose to involve family, friends, or professionals in your research and planning. Plan early so the person with dementia can participate and make choices whenever possible.

Check the tips below that you have already done or are in the process of doing, and add any of your own.

- ☐ Don't put off talking about finances and future care wishes
- ☐ Organize and review important documents
- ☐ Get help from well qualified financial and legal advisers
- ☐ Estimate possible costs for the entire disease process
- ☐ Look at all of your insurance options
- ☐ Find out for which government programs you are eligible
- ☐ Learn about income tax breaks for which you may qualify
- ☐ Explore financial assistance you can personally provide
- ☐ Take advantage of low-cost and free community services

Other suggestions include:

tip 9: make legal plans

Legal plans can ensure that the wishes of the person with dementia are carried out regarding health care, long-term care, finances, and decision making. If you and the person with the disease feel that there are legal issues that need attention, you might want to consider obtaining advice from an elder law attorney.

Check the tips below that you have already done or are in the process of doing now, and add any of your own.

- ☐ Ensure that all those named in the power of attorney document have a copy of and access to the original document.
- ☐ Name a successor (back-up) agent for power of attorney; your agent may one day be unable to act
- ☐ Consider a neutral third person as an agent to have power of attorney if family members don't get along.
- ☐ If a power of attorney for healthcare document and/or a signed living will is in place, give a copy to the physicians and other health care providers.
- ☐ See if the agent for the power of attorney for healthcare has authority to consent to a brain autopsy.
- ☐ Consider choosing an attorney or a bank to manage the estate if you lack a family member with the time or expertise

Other suggestions include:

tip 10: pay attention to home safety

Safety at home begins with adapting the environment to support the person with Alzheimer's as his or her abilities change over time. Now is the time to get those adaptations started. Be sure to re-evaluate home safety measures regularly as new issues may arise. It is a good idea to evaluate the person's home environment by going from room to room and assessing what could pose a danger to person. You can use the list below to help make that assessment. Check the items below that you currently have in place, and consider using the ideas to help keep the person with Alzheimer's and the family safe.

Assess fire and carbon monoxide risks

- ☐ Be sure to always have working fire extinguishers, smoke detectors and carbon monoxide detectors in the house and check batteries regularly.
- ☐ Make the use of fireplaces unavailable without supervision.

Beware of dangerous objects and substances

- ☐ Use appliances that have an auto shut-off feature.
- ☐ Install a hidden gas valve or circuit breaker on the stove .
- ☐ Monitor the use of power tools and outdoor grills.

Avoid injury during daily activities

- ☐ Install walk-in showers and grab bars in the shower or tub and at the edge of the vanity to allow for independent, safe movement.
- ☐ Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place - or remove rugs completely.

Adapt to vision limitations

- ☐ Remove throw rugs altogether to reduce the likelihood of tripping if the person has difficulty walking, or uses a cane or walker.
- ☐ Create an even level of lighting by adding extra lights to entries, outside landings, areas between rooms, stairways and bathrooms.
- ☐ Use night lights in hallways, bedrooms and bathrooms.

Firearm safety

- ☐ Keep firearms in a locked cabinet, firearm vault, safe or storage case.
- ☐ Lock ammunition in a place separate from firearms.
- ☐ Exercise full control and supervision over firearms at all times.
- ☐ Ask for help from local law enforcement if you are unfamiliar with firearm safety or if you choose to discard the weapon.
- ☐ Unload firearms when not in use.
- ☐ Remove the firearm from the living space.

Other suggestions include:

tip 11: pay attention to driving safety

Driving demands good judgment, quick reaction times and split-second decision making. A diagnosis of Alzheimer's disease alone is not a reason to take away driving privileges. But due to the progressive nature of Alzheimer's, a person with the disease will eventually be unable to drive.

It's often difficult to decide when to stop or limit driving. To help make this decision, get a driving evaluation from a certified professional. Contact the Alzheimer's Association (800.272.3900) for referrals to organizations in your community that can perform these evaluations.

Ideally, families should talk openly about driving soon after a diagnosis. They should make plans for how the person will get around when he or she can no longer drive.

Signs of unsafe driving

The following behaviors may be signs that it is time to stop driving. Check those that you notice:

- ☐ Forgetting how to locate familiar places
- ☐ Failing to observe traffic signals
- ☐ Making slow or poor decisions
- ☐ Driving at inappropriate speeds
- ☐ Becoming angry and confused while driving
- ☐ Hitting curbs
- ☐ Using poor lane control
- ☐ Making errors at intersections
- ☐ Confusing the brake and gas pedals
- ☐ Returning from a routine drive later than usual. The person may be wandering and getting lost in the car. Consider enrolling the person in MedicAlert + Safe Return.

tip 12: take care of yourself

Being a care partner for someone with Alzheimer's disease is emotionally taxing in the early stages, and also becomes physically demanding as the disease progresses. It is crucial that care partners pay attention to taking care of themselves in order to be able to help meet the needs of the person with dementia.

Check any of the following that apply to you regularly. Do you:

- ☐ Feel like you have to do it all yourself, and that you should be doing more?
- ☐ Withdraw from family, friends and activities that you used to enjoy?
- ☐ Worry that the person you care for is safe?
- ☐ Feel anxious about money and healthcare decisions?
- ☐ Deny the impact of the disease and its effects on your family?
- ☐ Feel grief or sadness that your relationship with the person isn't what it used to be?
- ☐ Get frustrated and angry when the person with dementia continually repeats things and doesn't seem to listen?
- ☐ Have health problems that are taking a toll on you mentally and physically?

If you checked any of the above, you may be experiencing stress related to being a care partner of someone with Alzheimer's disease.

While every situation is different, specific needs apply to all dementia care partners. Care partners notoriously put their own welfare and needs "on the back burner," often due to time constraints, lack of respite care, or lack of energy.

In order to be a healthy care partner, it can help to do the following. Check those you are already doing, and consider adding some new components of caring for yourself as a care partner.

To help you sustain your energy and emotions, be sure to:

- ☐ Take care of your own needs by making healthy habits a priority.
- ☐ Listen to your body; it will tell you if it is tired, hungry, or run down. These feelings are like red flags indicating that you need to reassess how you are taking care of yourself.
- ☐ Make and keep regular appointments with your own physician.
- ☐ Exercise regularly, keeping in mind that exercise can take the form of short bursts of activity that you enjoy.
- ☐ Eat right to sustain your energy and boost your immune system.
- ☐ Get enough sleep.
- ☐ Stay connected with others
- ☐ Maintain those hobbies that bring you relaxation and satisfaction.
- ☐ Let go of perfection.
- ☐ Ask for or hire help from others

For more information, resources and support, see the Alzheimer's Association's website at www.alz.org, or call our 24/7 Helpline at 1-800-272-3900.

Other suggestions include:
