

10 steps to planning for Alzheimer's disease & other dementias

A guide for family caregivers

Caring for a person with memory loss or dementia can be challenging. The following ten steps can help caregivers provide the best possible care for those with the disease, while maintaining their own health and well-being.

Step 1: Get a diagnosis as early as possible based on a thorough memory assessment or cognitive evaluation

When a family member or friend is showing signs of memory loss or other cognitive difficulties, it's time to talk to his or her primary doctor about these concerns. The primary doctor may evaluate the person or you may want to make an appointment with a geriatric specialist or at a memory assessment clinic. A good evaluation includes thorough physical, cognitive, and laboratory testing, as well as obtaining a detailed description of the cognitive changes that the patient and/or family have observed.

An early diagnosis is important because:

- There are many things that can cause memory loss and other cognitive changes, and the person's condition may be treatable or reversible.
- If a disease such as Alzheimer's is diagnosed, treatments are available that can delay the progression of symptoms and are most effective if started early in the disease process.
- Families learn more about what to expect and what the course of the illness may be and are better able to plan for the future together.
- The person with the disease can take a more active role in legal and financial planning decisions, learn tips and coping strategies, and choose how to prioritize the time remaining before symptoms worsen.

Available from the Alzheimer's & Dementia Alliance:

- ❑ Community resource guides with listings of memory assessment clinics
- ❑ Alzheimer's disease information and brochures
- ❑ Information about other dementias such as vascular dementia, dementia with Lewy Bodies, and frontotemporal dementia
- ❑ "Treating Alzheimer's Disease: A Guide to Medications" brochure
- ❑ Other information on getting a diagnosis and working with the doctor

Step 2: Educate yourself and others

Education is important because Alzheimer's and other dementia-causing diseases bring new and unfamiliar challenges and issues for families. Learning about the disease and how to manage it may:

- Let you know what to expect throughout the course of the illness.
- Help to alleviate the stress of the unknown.
- Help you make informed decisions and be prepared for the future.
- Help you learn effective caregiving skills and techniques in order to provide a better quality of life for your loved one at all stages of the disease.

Ways to educate yourself and your family:

- Have family members present at time of diagnosis and at follow-up meetings so that everyone hears the same information and is able to ask questions.
- Attend Alzheimer's & Dementia Alliance educational programs and support groups.
- Visit the Alzheimer's & Dementia Alliance website for up-to-date information.
- Read books, informational brochures, and handouts.
- Become familiar with local resources.

Available from the Alzheimer's & Dementia Alliance:

- "Crossing Bridges" - support and information series for persons with early memory impairment and their families
- Family education programs on a variety of topics
- Lending library – books, videos, and DVDs available for loan
- Information packets - brochures and handouts on a variety of topics
- Community resource guides - information about services in your area
- Helpline (888-308-6251) – telephone support available toll-free
- Individual and family consultation – specialists are available to talk with you on the phone or in-person to provide support and help in planning and problem-solving

Step 3: Get support from others

Trying to do it all yourself could exhaust you and affect your health. The support of family and friends can be an enormous help. .

- Be open to asking for help from friends, family, neighbors, faith community, etc.
- Use the community services available to you.
- Join a caregiver support group
- Talk with friends and family.

Available from the Alzheimer's & Dementia Alliance:

- Helpline (888-308-6251) – telephone support available toll-free

- ❑ Caregiver support groups
- ❑ Individual and family consultation – specialists are available to talk with you on the phone or in-person to provide support and help in planning and problem-solving

Step 4: Make future plans with family

It is important to plan early because:

- In the early stages, the person with Alzheimer’s or other dementia can still be actively involved in making decisions for the future.
- A plan will be in place as needs change or in case of a crisis situation.
- The family will know the person’s wishes, which may lessen confusion or disagreements when plans need to be implemented.
- Family members can each be clear on how they can help and what their limits are.

How to begin planning:

- Hold a family meeting involving as many family members and loved ones as possible.
- Get input from everyone including the person with Alzheimer’s or other dementia if he or she is still capable of participating.
- Identify potential future needs and how these will be met and by whom.
- Set up clear lines of communication.
- Be realistic and empathetic with each other.

Available from the Alzheimer’s & Dementia Alliance:

- ❑ Individual & family consultation – specialists are available to talk with you on the phone or in-person to help identify issues or to get ideas on how to plan a family meeting
- ❑ Handouts available on how to hold a family meeting
- ❑ Handouts and brochures on issues to consider when planning

Step 5: Begin legal and financial planning

Legal and financial planning should begin as soon as possible and includes putting in place documents that authorize another person to make health care and financial decisions as well as developing financial plans for long-term care coverage.

How to begin planning:

- Complete a *Health Care Power of Attorney* for yourself and for the person with Alzheimer’s or other dementia. This form appoints a family member or friend to be the health care agent and to make health-related decisions when the person is no longer capable. There are standard forms available through the Wisconsin Department of Health & Family Services and some social service and health providers.

- Complete a *Power of Attorney for Finances and Property*. This appoints an agent to handle financial matters for the person. Although standard forms are available, it is usually recommended that an attorney help prepare the POA for Finances and Property.
- Consult an attorney with experience in elder law to determine if there are other things you need to consider for your particular circumstances.

Available from the Alzheimer’s & Dementia Alliance:

- ❑ List of elder law attorneys in the area
- ❑ Brochures on legal and financial planning
- ❑ General information on legal and financial options available
- ❑ Legal & Financial Planning Seminar - presented several times each year by area attorneys with expertise in this area

Step 6: Make adjustments to support the person with dementia

- Make adaptations to accommodate changing needs and to provide a safe and supportive environment.
- Provide routine and structure to the day to lessen confusion and promote success.
- Adjust ways of communicating. People with dementia may find it increasingly difficult to express themselves in words and have trouble understanding what has been said, but the need for communication continues to be important even as the disease progresses. Try new approaches to listening and speaking.
- Connect the person to his/her environment through enjoyable involvement and activities that structure time and make the best of retained and existing abilities. You can continue to enjoy time together and share special moments!

Available from the Alzheimer’s & Dementia Alliance:

- ❑ Handouts on safety, activity planning, communication and more
- ❑ Helpline (888-308-6251) – telephone support available toll-free
- ❑ Individual and family consultation – specialists are available to talk with you on the phone or in-person to provide support and help in planning and problem-solving

Step 7: Use available services and assistance

Types of services you may need:

- In-home respite and companion care
- Home maintenance services (cleaning, yard work, etc.)
- Home health and personal care services
- Adult day programs
- Geriatric case managers
- Senior coalitions or county aging units

Financial assistance available in community

- Social Security Disability Insurance (SSDI) – for those under age 65
- Long term care programs
- Alzheimer’s Family & Caregiver Support Program (AFCSP)
- Medical Assistance (MA) – also called Medicaid
- National Family Caregiver Support Program (NFCSP)

Available from the Alzheimer’s & Dementia Alliance:

- Community resource guides – listings of services, agencies, and facilities in your area
- Brochures and information on how to access services and what to look for
- Legal & Financial Planning Seminar
- AFCSP assistance for eligible residents of Dane County

Step 8: Learn about facility care

Choosing facility care is never an easy decision for families. Yet, there may come a time when the person with dementia needs a more structured setting. Some facilities have “dementia-specific” units or “special care” units to provide specialized programming and care for persons with Alzheimer’s disease or a related disorder. It is important to remember that there is no “right” time for everyone. Each person and family is different, and there are many factors to consider.

Some factors to consider when making the decision:

- Is the person having increasing difficulty with personal care and needing more assistance?
- Is the home environment no longer safe for the person?
- Is caregiving taking a toll on the caregivers’ physical and emotional health?

Types of Facility Care:

- Residential Care Apartment Complex (RCAC)
- Adult Family Homes (AFH)
- Community Based Residential Facilities (CBRF)
- Nursing Homes

Available from the Alzheimer’s & Dementia Alliance:

- “Residential Care: A guide for choosing a new home” handout
- Information on when and how to make the decision regarding facility care
- Resource guides that list facilities in your area
- Caregiver education program: *Is it time for facility care?*

Step 9: Take care of yourself and manage your stress level

In order to be an effective caregiver, you need to maintain your own health and well-being. It's easy for caregivers to devote themselves totally to caregiving and neglect their own needs. Don't fall into that habit. Stress can manifest itself physically (blurred vision, digestive problems, high blood pressure), emotionally (depression, frustration, loss of self-esteem) and behaviorally (irritability, lack of concentration, loss of appetite). Be alert to your own stress symptoms and get help.

Ways to take care of yourself:

- Try to get adequate sleep and exercise, and maintain a healthy diet.
- Maintain friendships, interests, and hobbies.
- Have realistic expectations of yourself and your loved one.
- Take one day at a time and avoid anticipating the worst.

Available from the Alzheimer's & Dementia Alliance:

- ❑ Information and handouts on managing caregiver-related stress
- ❑ Helpline (888-308-6251) – telephone support available toll-free
- ❑ Individual and family consultation – specialists are available to talk with you on the phone or in-person to provide support and help in planning and problem-solving
- ❑ *Taking Care of You: Powerful Tools for Caregiving* classes
- ❑ Caregiver support groups

Step 10: Give yourself credit, not guilt

You're human. You may occasionally lose patience and do or say things you may regret. Remind yourself that you weren't perfect before you became a caregiver, and there's no reason to expect perfection now. Give yourself credit. We all do the best we can in our particular circumstances. You are there for your family member with dementia, and that's something to be proud of.

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