

10 Steps in Planning for the Future

Caring for someone with a progressive dementia brings about many new challenges and new things to learn. The following ten steps can help caregivers provide the best possible care for those with a progressive dementia, while maintaining their own health and well-being.

Step 1: Get a diagnosis as early as possible based on a thorough medical and memory evaluation. Talk to your loved one's primary doctor about your concerns. The primary doctor may evaluate your family member or friend, or refer him or her to a geriatric specialist or a neurologist. A good evaluation can help to rule out reversible and treatable causes of memory impairment; help your family to plan for the future; and may allow earlier treatment of a progressive dementia to delay symptoms.

How We Can Help: Listing of local neurologists; brochures and handouts on the diagnosis of the dementias; a list of questions to ask your doctor; and information about medications used to treat a progressive dementia.

Step 2: Educate yourself and others. Learn about dementia and how to manage it. This can help you know what to expect throughout the course of the disease and help you make better decisions about how to help care for your loved one.

How We Can Help: Educational programs (Savvy Caregiver series, Caregiving 101 webinars); family consultations; support by telephone; brochures and handouts about Alzheimer's disease and related dementias; lending library; and recommended books/videos/websites about the disease or certain topics of interest.

Step 3: Get support from others. Trying to do it all on your own is not only exhausting, but can have a negative impact on your personal health. The support of family and friends can be an enormous help.

How We Can Help: Caregiver support groups; support by telephone; family consultations.

Step 4: Make future plans with family. Hold a family meeting (including the person with the progressive dementia if he or she is still capable of participating) to identify future needs and how these needs will be met and by whom. Set up clear lines of communication with one another.

How We Can Help: Family consultations; handouts about how to organize a family meeting; and what issues to consider during the meeting.

Step 5: Begin legal and financial planning. Begin this as soon after diagnosis as possible. This includes putting in place documents that authorize another person to make health care and financial decisions, (Durable POA) as well as developing financial plans for long term care coverage.

How We Can Help: Listing of local legal and financial planning services; educational seminars on financial and legal planning; family consultations; and brochures on legal and financial planning.

Step 6: Make adjustments to support your loved one. This can include environmental safety changes, providing routine and structure to your loved one's daily agenda, communication strategies, and involving your loved one in enjoyable activities geared towards his or her abilities.

How We Can Help: Brochures and handouts on enhancing your loved one's home environment; info on communicating effectively with your loved one; planning daily activities; caregiver support groups; support by telephone; family consultations; and mini-grant funds for items that will help your loved one maintain a safe and productive life.

Step 7: Utilize available resources to help. Types of resources you may need include: in-home respite and companion services, chore services, meal services, home health services, care coordination services, adult day programs.

How We Can Help: Care coordination services; assistance to find respite services, chore services, or consumer-directed personal care attendant services; caregiver support groups (a great way to learn about local resources); support by telephone; family consultations and community referrals; and mini-grant funds for some community resources.

Step 8: Learn about facility care. You may be able to provide care for your loved one at home throughout the disease. Nevertheless, it is good to know your options for assisted living homes, nursing homes, and other facility care.

How We Can Help: Care coordination services; family consultations; listings of licensed assisted living facilities in your area; brochures and handouts on choosing a new home and how to assess facilities.

Step 9: Self-care. Take care of yourself and manage your stress level. Be alert to your own health and well-being and get help when needed. Get adequate sleep and exercise, and maintain a healthy diet. Maintain friends, interests, and hobbies. Take one day at a time and take a break from the caregiving role as often as possible.

How We Can Help: Caregiver support groups; support by telephone; individual consultations; handouts on relieving stress and caregiving; and educational programs.

Step 10: Give yourself credit, not guilt. You are human. You will 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 is no reason to expect perfection now. We all do the best we can in our particular circumstances.

You are there for your loved one, and that's something to be proud of!

How We Can Help: Support by telephone and individual consultations.