

## **After the Diagnosis: A Guide for Family Caregivers**

### **Get a complete diagnosis as early as possible**

A good evaluation includes physical, cognitive, and laboratory testing, as well as obtaining a detailed description of the cognitive changes that the patient and/or family have observed. If possible, get a diagnosis that goes beyond “dementia” and identifies the underlying disease process. This will help everyone better understand symptoms, treatments, and the expected course of the illness. Ask for more information if you left the diagnosis appointment confused or uncertain.

Because many conditions can cause cognitive changes, and some of these may be treatable, it is important to get assessed as early as possible. Treatments to potentially delay the progression of Alzheimer’s disease symptoms are most effective when started early in the disease process. An early diagnosis also allows the person living with the diagnosis to take a more active role in legal and financial planning decisions, learn coping strategies, and choose how to prioritize the time remaining before symptoms worsen.

### **Take care of your emotional needs**

It is normal for caregivers to have many different feelings and thoughts after their loved one receives a diagnosis of dementia. Shock, sadness, anger, relief, fear, guilt, grief—these are all typical responses. Instead of strong emotions, some people feel physical sensations such as fatigue or pain. These reactions are normal, and it is important to acknowledge them. Give yourself space and time to experience your feelings. Write in a journal. As your loved one permits, talk to others, including professionals like counselors or clergy, about what you are going through.

### **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 can help you know what to expect over the course of the illness and how to manage it. Education can help alleviate the stress of the unknown, provide the chance to make informed decisions, and better prepare everyone for the future. You can learn effective caregiving skills and techniques to provide a better quality of life for your loved one at all stages of the disease.

### **Get support**

Trying to do it all yourself can exhaust you, affect your health, and reduce your effectiveness as a caregiver. Support from others can be an enormous help. Be open to asking for help from your friends, family, neighbors, faith community, etc. It is important to stay connected to those people who make up your circle of support. Identify and use community services. Caregivers often benefit from joining a support group.

## **Make plans for health care, finances, and long-term care**

It is important to plan early when the person with dementia can still be actively involved in making decisions for the future. Putting a plan in place is critical as needs change or in case of a crisis. You may wish to hold a family meeting involving as many family members and loved ones as possible. Shared planning allows the family to know the wishes of the person living with the diagnosis, which may lessen confusion or disagreements when plans must be implemented.

Legal and financial planning should begin as soon as possible. This 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. For instance:

- Encourage the person with the diagnosis to complete or revisit their health care advance directives—the Power of Attorney for Health Care (POA-HC) and Living Will. Complete your own POA-HC if you don't have one; if you do have one, review your current agent designations.
- Encourage your loved one to complete a will, a living trust, and a Power of Attorney for Finances and Property. The Power of Attorney appoints an agent to handle financial matters.
- Talk with staff at the county Aging and Disability Resource Center (ADRC) for information on home care, respite care, and long-term care options and financing.
- Consult an attorney with experience in elder law to determine what other things you need to consider for your particular circumstances.

## **Consider safety issues**

Determine if the person living with dementia should continue to drive and, if not, take necessary actions to prevent it. Seek out a home safety evaluation (the cost may be covered with a physician's order). The evaluation will alert you to fall hazards, fire issues, and inadequate lighting. Monitor medication compliance and talk to a pharmacist about medication reminders or automated pill dispensing systems. Be attentive to potential financial errors or exploitation.

## **Make adjustments to support the person with dementia**

Setting up routines and structuring the day can decrease confusion and promote success. Make adaptations as needed to accommodate changing needs and to provide a safe and supportive environment. 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!

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 as the disease progresses. Adjust your ways of communicating and try new approaches to listening and speaking.

## **Use available services and financial assistance**

Caregivers find many types of local services critical to keeping their loved ones safe and at home. These include in-home respite and companion care, home health and personal care services such as bathing assistance, and home maintenance services such as cleaning or yard work. Adult day programs provide both an enriching experience for loved ones and respite for caregivers. Sources of financial assistance for these services may include Social Security Disability Insurance (SSDI), for those under age 65; the Alzheimer's Family and Caregiver Support Program (AFCSP) and the National Family Caregiver Support Program (NFCSP) for respite support; long-term care programs; Medical Assistance (MA), also called Medicaid; and Veteran benefits through the VA.

## **Learn about facility care**

Choosing facility care is never an easy decision for families. Yet, there may come a time when the person living with dementia needs a more structured and supportive setting. Thinking about this now can be helpful. Some facilities have dementia-specific “memory care” units to provide specialized programming and care for persons with dementia. Many facilities have waitlists. Consult ADAW staff for more information on considerations for facility placement. You may find our handouts and family education program helpful when evaluating facilities. Support group members who have been through the placement process can offer invaluable experience and insight.

## **Take care of yourself and manage your stress level**

To be an effective caregiver, you need to maintain your own health and well-being. It’s easy—and dangerous—for caregivers to devote themselves totally to caregiving and neglect their own needs. Taking care of yourself includes getting adequate sleep and exercise, choosing a healthy diet, and maintaining friendships, interests, and hobbies.

Stress can manifest itself physically (e.g., blurred vision, digestive problems, high blood pressure), emotionally (e.g., guilt, depression, anxiety, frustration, loss of self-esteem), and behaviorally (e.g., irritability, poor concentration, loss of appetite). Be alert to your own stress symptoms and remember that depression and anxiety are common among caregivers. If painful feelings, nagging thoughts, or physical symptoms last for weeks, and especially if they affect your day-to-day functioning, see your health care provider.

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