



After the Diagnosis: A Guide for Persons Living with Dementia

Take care of your emotional needs

It is normal to have many different feelings and thoughts after receiving a dementia diagnosis. Shock, sadness, anger, guilt, relief, fear, grief—you may feel these and other emotions. Some people feel physical sensations such as fatigue or pain. All these reactions are normal, and it is important to acknowledge them. We suggest that you give yourself space and time to experience your feelings. Talk to loved ones, a counselor, or a clergy member. Write in a journal. Join a support group. Depression and anxiety are common among those with a diagnosis. 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.

Recognize that you are not alone and still have a purpose

Connect with support groups of others who are coping with the same diagnosis. ADAW offers a weekly cognitive enhancement group called “Meeting of Minds,” monthly “Memory Cafés” for persons with a diagnosis and their care partners, and small peer groups that meet regularly for conversation and support. These can improve your mood and help remind you that you are not alone. Our agency and others depend on you for your advice, wisdom, and direction. You still have purpose and can live a healthy, active, and meaningful life with dementia.

Seek support

The dementia journey takes a team effort. Decide who to tell about your diagnosis, keeping in mind that some family and friends will handle this better than others. Call a family meeting or a gathering of close friends to get advice and make plans. Now is the time to start practicing the skills of asking for and accepting help from others—whether family, friends, neighbors, or your faith community. Follow up on referrals to agencies and services for help with routine tasks such as cooking, paying bills, transportation, shopping, or yard work.

Learn more about your diagnosis

Your health care providers will want to partner with you to manage your health, so it will help them if you know about your condition. Getting more information is especially important if you left your diagnosis appointment confused or uncertain. Meet with your health care provider or the professional who diagnosed the disease. Try to bring someone with you for support and as “another pair of ears.” If needed, ask your provider to review the tests you took and your results. Get information about your specific disease, its progression, and possible medications. Ask if they will manage your care going forward, or if you should see someone else.

Get regular health check ups

Your primary health care provider is a critical member of your care team and you should see them regularly for health check-ups. If possible, always bring someone with you to your appointments. Talk to your provider about monitoring and controlling those health conditions—such as high blood pressure or diabetes—that can affect thinking and memory. Tell your

provider about all medications you are taking—some over-the-counter medications can make memory problems worse. Report any change in symptoms.

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

Complete or revisit your health care advance directives—your Power of Attorney for Health Care (POA-HC) and your Living Will. The POA-HC indicates who will make your health care decisions when you no longer can. The Living Will details your wishes at end of life. Get assistance with these documents through your health care organization or an attorney.

Advance directives for financial and estate management include a will, a living trust, and a Power of Attorney for Finances. If possible, find an attorney who specializes in legal work with older adults (sometimes referred to as an elder law attorney) or with adults with disabilities.

Meet with staff of the ADRC or other aging agency to discuss financing of long-term care, including home care, senior housing, assisted living, and nursing care facility placement.

Watch out for your safety

Dementia can affect attention, memory, judgement, reaction time, wayfinding, and vision. Ask your doctor whether you should continue to drive. You may wish to get a driving evaluation or pick a trusted family member or friend to give you honest feedback on your driving. 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. Ask someone to monitor your medication compliance and talk to a pharmacist about medication reminders or automated pill dispensing systems. Set up trusted supports to protect you from financial errors or exploitation.

Choose a healthy lifestyle

Research suggests that a healthy, active lifestyle may slow the symptoms of dementia. Studies have confirmed the benefits of aerobic exercise, good nutrition (a Mediterranean-style diet), challenging mental activity, regular social contact, adequate sleep, and reduced stress.

Experts often recommend that persons with dementia stop using tobacco and reduce or stop using alcohol. See your provider for advice on the most important lifestyle changes for you.

Consider participating in clinical trials

Talk to your doctor about dementia trials or studies. You may wish to contact the Wisconsin Alzheimer's Disease Research Center, located in Madison, Wisconsin. Connecting with dementia researchers can give you access to the newest research results and treatments. It can also allow you to positively affect the lives of many others, including future generations.

Stay connected and active

Social connections and meaningful activities are good for your brain health, protect against depression, and offer hope and meaning. As much as you can, maintain employment or volunteering, a regular social calendar, creative activities, pleasurable pursuits, and spiritual practices. Some people use this time to act on life-long dreams or to complete unfinished business. Others advocate for dementia research, dementia-friendly communities, or better dementia care. Whatever you choose, tap into your deepest dreams, values, and passions.

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