

What Now ...

Navigating a
Dementia Diagnosis



**DEMENTIA
ALLIANCE**

of North Carolina

A STATE OF CARING



Early diagnosis of dementia is important and gives the person diagnosed and their family time to plan for the future, have important conversations and find helpful resources.

There are many emotions that go along with this diagnosis, and everyone will cope differently. But as hard as it is to have a dementia-causing disease confirmed by a healthcare professional, it is an opportunity to plan for the future.

Conditions causing dementia may result in different prominent symptoms (memory is not always the first area affected) but all eventually lead to a person needing help from others. Having a say in what that help looks like, what shape it takes, can be an important part of this journey.

While each person is different and has a different experience with dementia, learning as much as you can about the disease or condition you are living with is critical. It helps to better understand what is happening in the brain and what to expect as things progress.

Learn about your type of dementia:

- Visit www.dementianc.org/education/common-

dementias/ for descriptions of many types of dementia. Dementia Alliance can help with all of them

- In addition, there are organizations for several specific types, such as **Frontotemporal degeneration** - (www.theaftd.org), **Lewy Body dementia** (www.lbda.org), **Huntington's disease** (hdreach.org)



Learn about your type of dementia

When diagnosed with dementia, other illnesses don't simply go away. And sometimes, such as with high blood pressure, they can be related to the type of dementia you have.

Continue with regular medical care:

- Care for anything else you have going on (diabetes, heart issues, etc.)
- Consider consulting with a specialist, for example, a

neurologist specializing in conditions causing dementia

I *t takes a village* is not just an expression. No one can do this alone. Both the person living with dementia and their caregiver will need a lot of supports.

Build your care team:

- Teams can be diverse depending on your needs. Set up your team by strengths, not everyone is cut out to do everything. Perhaps someone

Continue with regular medical care



lives a distance away but knows a lot about technology, they can be the person to set up video conferencing for the family. Maybe your neighbor can't help with much, but can make a delicious meal to share

- Friends, neighbors, colleagues, congregations
- Professional Geriatric Care Managers, Occupational Therapists, Speech Language Pathologists and Physical Therapists
- Volunteers, other people dealing with similar challenges, your attorney, pharmacist, support group, etc. The list goes on ...

Every county has resources to help along the dementia journey. And while it may seem overwhelming, it is helpful to know what services are available before you need them.

Learn about services in your area:

- Area Agencies on Aging, Councils on Aging, memory cafes, adult day programs, respite programs, and senior centers



- Library, online shopping, delivery services, lawn care
- Home Care, Independent Living options, Assisted Living, Memory Care and Skilled nursing facilities
- Hospice
- Support Groups

Now is the time to be sure your wishes are documented and your care needs will be met.

Do legal, financial, and healthcare planning:

- Choose a power of attorney (POA)
- Make a will
- Organize your information
- See an Elder Law Attorney
- Explore your options for advance directives (healthcare planning and end of life documents)
- Explore Social Security disability benefits and Veterans Benefits
- Share the location of important documents with your family/care team

Prepare your home to safely age in place.

Focus on safety inside & outside of your home:

- Install ramps and grab rails where needed
- Explore technology - motion-detecting lights, alarms, and cameras

- Identify tripping and fall hazards - throw rugs that easily slide or bunch up and thresholds between rooms, especially where the floor changes from hardwood floors to carpeting, etc.



- Kitchen Safety - are stove burners being left on or inappropriate cookware/utensils being used in the microwave?
- Are weapons (guns, knives) present? If possible, remove from home entirely or store without ammunition. Keep everything locked up
- Driving - Speak to your healthcare provider about your concerns and consider getting a driving evaluation by a professional evaluator



- Identification - Acquire medical alert tags and services and take photos before you go out so you know exactly what your person is wearing that day

Caregivers often become ill from both exhaustion and psychological stress.

Take Care of Yourself:

- Pace yourself, ask for help
- Consider joining a support group
- Don't compare yourself to other caregivers. Everyone's situation is different and everyone approaches things differently



- Check out our *Caring for the Caregiver* booklet. Download your copy at: www.dementianc.org/CaringfortheCaregiver

Take Care of Yourself





Connect with researchers and other brain health organizations.

Participate in clinical trials:

- Clinical trials can be for the person living with dementia or the well-spouse, caregiver, as well as other family members
- Check out the NC Registry for Brain Health - the first registry of its kind in North Carolina. The Registry is designed to increase awareness of Alzheimer's disease and related disorders and to connect North Carolinians of all ages to research opportunities designed to improve brain health. Visit www.ncbrainhealth.org/

- Explore ClinicalTrials.gov - a database of privately and publicly funded clinical studies conducted around the world. Search by illness, location, and other keywords. Visit www.clinicaltrials.gov/

Let our dementia navigator help guide your family's journey. For more than 40 years, Dementia Alliance of North Carolina has provided educational programs and support services for families across the state, and has funded dementia research at our state universities and institutions.

Call or visit us today at:



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