



## Now What?

### *Next Steps After a Diagnosis of Alzheimer's Disease or Other Dementias*

A diagnosis of Alzheimer's disease or other dementia disorder can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Use this checklist to get started.

#### **Learn about Alzheimer's disease or Other Dementias**

Confirm the diagnosis. Being informed will help you know what to expect as the disease progresses. Learning is ongoing. Continue to read and ask questions. Here are some resources:

- **Alzheimer's Disease Education and Referral (ADEAR) Center:** 1-800-438-4380; [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)
- **Alzheimer's Association-Greater Illinois Chapter:** 1-800-272-3900; [www.alz.org/illinois](http://www.alz.org/illinois)
- **Alzheimer's Foundation of America:** 1-866-232-8484; [www.alzfdn.org](http://www.alzfdn.org)
- **The Association for Frontotemporal Degeneration:** 1-866-507-7222 [www.theaftd.org](http://www.theaftd.org)
- **The Lewy Body Dementia Association:** 1-800-539-9767 [www.lbda.org](http://www.lbda.org)
- **Cure PSP:** 1-800-457-4777 [www.psp.org](http://www.psp.org)
- Local hospitals may have educational programs about Alzheimer's disease/dementia

#### **Stay healthy**

- Get regular medical care - Make regular appointments with your primary care doctor and/or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist).
- Be active! Getting exercise helps people with Alzheimer's feel better and helps keep their muscles, joints, and heart in good shape. For tips, see [www.nia.nih.gov/Go4Life](http://www.nia.nih.gov/Go4Life)
- Eat a well-balanced diet that includes fruits, vegetables, and whole-grain products: [www.nia.nih.gov/health/publication/whats-your-plate](http://www.nia.nih.gov/health/publication/whats-your-plate)  
<https://www.rush.edu/news/diet-may-help-prevent-alzheimers>
- Follow a regular daily routine to structure the day.
- Use professional counselors to help cope with changes.

□ **Illinois Memory and Aging Specialty Clinics** – talk to your doctor about going to a specialized memory disorders clinic. Below is a list of specialty clinics in Illinois; some may ask for a referral from your doctor.

- Advocate Memory Center [www.advocatehealth.com/memorycenter](http://www.advocatehealth.com/memorycenter)
- Alexian Brothers Memory & Cognitive Disorders Center [www.alexianbrothershealth.org/neurosciences/services/memory-disorder](http://www.alexianbrothershealth.org/neurosciences/services/memory-disorder)
- Northshore University Neurological Institute [northshore.org/neurological-institute/centers-and-programs/alzheimers-disease-and-memory-disorders-program/](http://northshore.org/neurological-institute/centers-and-programs/alzheimers-disease-and-memory-disorders-program/)
- Northwestern Medicine Neurobehavior and Memory Clinic [www.brain.nm.org](http://www.brain.nm.org)
- Northwestern Medicine Central DuPage Hospital [www.cadencehealth.org/what-we-offer/specialized-care/neurosciences/dementia#locations](http://www.cadencehealth.org/what-we-offer/specialized-care/neurosciences/dementia#locations)
- Rush Memory Clinic [www.rush.edu/services/memory-clinic](http://www.rush.edu/services/memory-clinic)
- SIU School of Medicine Memory and Aging Clinic [www.siumed.edu/alz](http://www.siumed.edu/alz)
- University of Chicago Center for Comprehensive Care and Research on Memory Disorders <http://www.uchospitals.edu/specialties/neurosciences/memory/>
- UIC Memory and Aging Clinic: [http://chicago.medicine.uic.edu/departments\\_programs/departments/neurology/patient\\_care\\_neurology/memory\\_aging\\_clinic](http://chicago.medicine.uic.edu/departments_programs/departments/neurology/patient_care_neurology/memory_aging_clinic)

□ **Start important conversations**

- Share information about the disease and your needs with key family and friends. Talk about what is changing and its impact on yourself and others. Acknowledge there will naturally be different perspectives and experiences.
- Teens and young children have specific needs related to this difficult conversation. For some help, visit the Alzheimer’s Association’s site for Kids & Teens [http://www.alz.org/living\\_with\\_alzheimers\\_just\\_for\\_kids\\_and\\_teens.asp](http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp)
- **If you are working**
  - If you have problems performing your job, consider reducing your hours or switching to a less demanding position.
  - Consult your employer’s HR department or employee assistance program about family leave, disability benefits, and other employee benefits.
  - Find out if you qualify for Social Security disability benefits through “compassionate allowances.” Visit [www.socialsecurity.gov/compassionateallowances](http://www.socialsecurity.gov/compassionateallowances) or call 1-800-722-1213.

## Do some legal, financial, and long-term care planning

- Get information to help you plan: [www.nia.nih.gov/alzheimers/topics/legal-and-financial-planning](http://www.nia.nih.gov/alzheimers/topics/legal-and-financial-planning)
- Prepare or update your will, living will, healthcare power of attorney, and financial power of attorney. To find a lawyer, contact your local bar association or the **National Academy of Elder Law Attorneys**: [www.naela.org](http://www.naela.org)
- Learn about care you may need and how to pay for it: [www.longtermcare.gov](http://www.longtermcare.gov)
- Determine eligibility for Veterans Administration benefits.
- Explore getting help to pay for medicines, housing, transportation, and more. Visit the **National Council on Aging**: [www.benefitscheckup.org](http://www.benefitscheckup.org)

## Find local services and support

- **Illinois Department on Aging** 1-800-252-8966; [www.illinois.gov/aging](http://www.illinois.gov/aging)
- **Illinois Department of Rehabilitation Services**; [www.dhs.state.il.us](http://www.dhs.state.il.us)
- **Alzheimer's Association-Greater Illinois Chapter**: 1-800-272-3900; [www.alz.org/illinois](http://www.alz.org/illinois)
- **Alzheimer's Foundation of America Helpline**: 1-866-232-8484; [www.alzfdn.org](http://www.alzfdn.org)
- Contact relevant local healthcare, social service agencies, or other community organizations such as churches or community centers

## Get help as needed with day-to-day tasks

- Use simple memory aids like a notepad or sticky notes to jot down reminders, a pillbox to keep medications organized, and a calendar to record appointments.
- Ask your doctor for a referral to occupational, physical, and or speech therapist for evaluation and techniques to maximize abilities. These professionals can teach you ways to stay independent.
- Ask family members or friends to find local services to help with routine tasks, such as cooking, paying bills, transportation, or shopping.
- Consider using technology solutions for medication management, safety (e.g., emergency response, door alarms), and other care.
- See tips about coping daily and more: [www.alz.org/living\\_with\\_alzheimers.asp](http://www.alz.org/living_with_alzheimers.asp)

## Be safe at home and in your community

- Keep doing things that are important and enjoyable to you such as visits with family and friends, hobbies, and outings.
- Get home-safety tips: [www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease](http://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease)
- Ask your doctor to order a home-safety evaluation through a recommended home health care agency. Medicare may cover the cost.
- Consider joining the MedicAlert® + Alzheimer's Association Safe Return® program: [www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp)
- Consider using a GPS tracking or similar device

## **If you live alone**

- Develop a support system: Identify someone who can visit you regularly and be an emergency contact.
- If you are at risk of falling, order an emergency response system. A special pendant or bracelet lets you summon help if you fall and can't reach the phone.
- Get tips about self-care, preventing falls, staying connected, and more: [www.alz.org/i-have-alz/if-you-live-alone.asp](http://www.alz.org/i-have-alz/if-you-live-alone.asp)
- Stick with familiar places, people, and routines. Simplify your life.

## **Stay safe on the road**

- Talk with your doctor if you become confused, get lost, or need lots of help with directions, or if others worry about your driving.
- Get a driving evaluation. Ask your doctor for names of driving evaluators, or visit the **American Occupational Therapy Association**: [http://myaota.aota.org/driver\\_search](http://myaota.aota.org/driver_search)
- Learn about driving safety: [www.nia.nih.gov/health/publication/older-drivers](http://www.nia.nih.gov/health/publication/older-drivers)

## **Consider participating in research**

- Ask your doctor about clinical trials or studies at local medical centers or universities.
- Contact an **Alzheimer's Disease Center** for assessment and potential research opportunities.
- Search for a clinical trial or research study near you:
  - **ADEAR Center**: [www.nia.nih.gov/alzheimers/clinical-trials](http://www.nia.nih.gov/alzheimers/clinical-trials)
  - **TrialMatch**: [www.alz.org/trialmatch](http://www.alz.org/trialmatch)
- Learn more about clinical trials and other research studies:
  - **ADEAR Center**: [www.nia.nih.gov/alzheimers/volunteer](http://www.nia.nih.gov/alzheimers/volunteer)
  - **National Institutes of Health**: [www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)
- Some research studies will ask for brain or other tissue donation. Plan early if interested in brain autopsy/donation