



Dementia Resource Guide

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What is Dementia?

Dementia is a set of symptoms including cognitive decline, changes in thinking and problem solving skills, memory loss, changes in perception/senses, confusion with time and place, social changes, difficulty speaking, poor judgment, sleep issues, hallucinations, and many more.

Different diseases cause dementia. Alzheimer's Disease is the most common cause of dementia, but it's not the only cause. Other types of dementia include Lewy body dementia, vascular dementia, frontotemporal degeneration, and others.

Dementia

Myths

&

Facts

Myth

Dementia means memory loss.

Fact

Dementia describes a set of symptoms. Memory loss is only a part of dementia. People with dementia experience sleep issues, personality changes, loss of balance, changes in perceptions, and many other symptoms.

Myth

Dementia only affects older adults.

Fact

Age is the biggest risk factor for dementia, but many people under age 60 have dementia.

Myth

There is no way to reduce your risk for dementia.

Fact

Dementia is caused by both genetic and lifestyle factors. Healthy lifestyle changes may help reduce a person's risk for dementia by up to 45%. Modifiable risk factors include: managing hearing loss, vision changes, cholesterol, diabetes, hypertension, obesity, and depression; reducing smoking and alcohol intake; eating healthy, exercising, and engaging in social activities. Learn more: <https://www.thelancet.com/infographics-do/dementia-risk>

Myth

Dementia is a normal part of aging.

Fact

Not everyone will get dementia when they get older. Dementia is common in older adults, but it is not normal.

Myth

People with dementia can no longer live fulfilling, fun, or happy lives.

Fact

People with dementia can continue to do many things they enjoyed before. Although some adjustments may need to be made, they can still lead fulfilling lives and contribute to the greater community.



Myth

Most people with dementia live in nursing homes.

Fact

The majority of people with dementia live in their own homes and utilize community services.

According to the Alzheimer's Association, at least 62,000+ people are living with dementia in Iowa and over 98,000+ people are caring for someone with dementia in Iowa.

To learn more, visit: nia.nih.gov/health/alzheimers-and-dementia

What's Next

Next steps after signs of dementia

Having concerns about the onset of dementia or receiving a diagnosis can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Use these resources to help you get started.



How to Get a Cognitive Screening or Diagnosis

If you or a loved one is showing signs of dementia, the first step towards getting a diagnosis is by talking to a doctor. Many doctors will perform a cognitive screening. Depending on the results, the doctor may make a referral to a neurologist for further testing and brain scans.

Take charge of your brain health: schedule your Medicare Annual Wellness Visit cognitive assessment! A Medicare Annual Wellness Visit (AWV) is a yearly appointment with a primary care provider. The AWV is free for Medicare part B beneficiaries. Cognitive assessments have been covered by Medicare as part of the AWV. This assessment is non-invasive and can provide a baseline to assess for change over time with your cognitive functioning.

- ▶ Learn more about memory screenings here:
www.alz.org/professionals/health-systems-clinicians/cognitive-assessment
- ▶ Schedule a virtual screening here:
<https://alzfdn.org/get-a-free-screening/>
- ▶ Get a screening in Cedar Falls, at UNI's Dementia Simulation House
<https://csbs.uni.edu/family-aging-counseling/centers-initiatives/dementia-simulation-house>
- ▶ Advocate to Doctors and Medical Professionals
 - Discuss medication interactions, possible treatment or intervention plans, home safety, future planning, symptoms, and behaviors
 - Check out lists of specific questions:
 - www.alz.org/alzheimers-dementia/treatments/questions-for-your-doctor

Learn More About the Disease & What to Expect

Being informed about the disease will help you know what to expect as the disease progresses. Dementia is progressive and fatal. Progression will look different for each person depending on their situation and diagnosis.

- ▶ **Early/Mild Stage** - May be able to live independently, drive, or work. Symptoms are mild and sometimes not easily recognized.
- ▶ **Middle/Moderate Stage** - More difficulty with everyday tasks and some changes in personality; requires increasing levels of care. Often the longest stage; may last for several years.
- ▶ **Late/Severe Stage** - Often requires 24/7 care. Increased difficulty with communicating, recognizing surroundings, walking or other physical activities.
- ▶ **Learn More:**
 - Become a Dementia Friend to learn basics and communication strategies. Visit the Dementia Friendly Iowa website at www.dementiafriendlyiowa.org or call 319-287-1192
 - Caregiver Training with Iowa Geriatric Education Center (IGEC) visit <https://igec.uiowa.edu/caregiver-training>
 - Visit the UNI Dementia Simulation House | <https://bit.ly/DementiaSimulationHouse>
 - Alzheimer's and related Dementias Education and Referral (ADEAR) Center www.alzheimers.gov | 800-438-4380
 - Alzheimer's Association www.alz.org | 800-272-3900 (Online and in-person educational events)
 - Family Caregiver Alliance www.caregiver.org | 800.445.8106
 - Local hospitals and community centers may have educational programs about Alzheimer's disease and related dementias
 - Stages: <https://bit.ly/AlzheimersDementiaStages>

Communication Strategies for Caregivers

- ▶ Changes that come with dementia can make communication difficult. These strategies can reduce frustration and help caregivers maintain connection.”
 - **Be aware of your feelings.** Your tone of voice or other non verbals may communicate your attitude and agitate your loved one.
 - **Avoid correcting or criticizing.** Connect instead; their reality is real to them, and we need to step into their world.
 - **Be patient.** Simplify your sentences and leave time for their response
 - **Offer a guess.** If they're having trouble with a word, offer a guess.
 - **Avoid quizzing.** Try not to ask “remember when?” or put the person on the spot.
 - **Be specific.** Avoid vague statements.
 - **Turn negatives into positives.** Instead of saying no, offer a different option.
 - **Learn triggers for behaviors.** Aggression can be a sign of an underlying trigger such as fear, hunger, boredom, fatigue, etc.
 - Learn more:
 - Utilize Trualta, a free online platform with answers for caregiving challenges.
 - Explore online lessons and events. Learn more: <https://ltss-iowa-trualta.com/>

Options for Additional Care

Different living options meet varying needs of a person with dementia.

- ▶ Care options include:
 - In-home Services to Support Independent Living (may include adult day centers as a respite option)
 - Assisted Living
 - Nursing Home / Memory Care
- ▶ These options may have wait lists; contact and explore options in advance to prepare for higher levels of care needs as the dementia progresses.
- ▶ Discuss with your physician other supportive options such as speech therapy, occupational therapy, physical therapy, palliative care, and more.
- ▶ Discuss options available in your community with your local area agency on aging.
- ▶ Family Care Consultations via phone are available through the Alzheimer's Association at 800-272-3900

Legal & Financial Planning

It is important to handle legal affairs as early as possible to protect the rights and well-being of a person with dementia. As cognitive capacity decreases, the ability to make sound and safe decisions can be affected. Speak with a lawyer about Advanced Directives. If funding a lawyer is of concern, Iowa Legal Aid may provide free legal assistance to individuals 60 and older. Visit www.iowalegalaid.org or call 1-800-992-8161.

- ▶ To find a lawyer visit: <https://www.iowabar.org/?p-g=Find-A-LawyerHP>
- ▶ For legal assistance, visit: www.iowalegalaid.org/ or call 1-800-992-8161
- ▶ Health Insurance (Medicare & Medicaid)
 - Medicare: Government health insurance program provided to people 65 and older and those with certain medical diagnoses.
 - Questions about Medicare and other insurance choices can be answered. Call 1-800-351-4664, (TTY 1-800-735-2942) or visit <https://shiip.iowa.gov/find-resources/find-counselor> to find a SHIIP–SMP volunteer near you.
- ▶ Medicaid: Government health insurance program administered by Iowa Department of Human Services. Financial and medical eligibility requirements vary. Benefits vary; may include coverage for in-home supports and long term care.
 - Elderly Waiver – Medicaid program that assists with funding in-home services and medical costs.
 - Learn more or apply at: <https://hhs.iowa.gov/medicaid> or contact the local Area Agency on Aging office for application assistance.

Planning Ahead In Case Your Loved One Can No Longer Make Decisions

- ▶ Schedule an appointment with a lawyer to discuss...
 - A health care/medical power of attorney–someone to make health care decisions
 - A general/financial power of attorney - to name someone whom you want to manage your finances
 - A “Living Will” - to detail medical treatment desires if not able to give informed consent
- ▶ Ensure your partner or person appointed as general power of attorney has access to legal documents and knowledge of accounts, investments, and property.

Be Safe on the Road

Talk with your doctor if you or your loved one becomes confused, gets lost, needs help with directions, or if others worry about your driving.

- ▶ Find where to get a driving assessment here: <https://www.aota.org/practice/clinical-topics/driving-community-mobility/driving-practitioner-direct-ory>
- ▶ Learn more:
 - Visit the Iowa DOT website to understand steps on what to do if your loved one is no longer safe to drive: <https://bit.ly/RetiringFromDriving>
 - Starting a conversation with your loved one about driving: <https://bit.ly/DementiaDrivingConversation>
 - <https://nia.nih.gov/health/safety/driving-safety-and-alzheimers-disease>
 - <https://bit.ly/HomeAndCarSafetyGuides>

Be Aware of Abuse

People living with dementia are at increased risk of elder abuse due to greater dependence on others and difficulties communicating or reporting mistreatment. Recognizing the signs of abuse helps protect their safety, dignity, and well-being.

- ▶ If you suspect abuse, call Dependent Adult Protective Services (Iowa HHS)
 - 1-800-362-2178 (toll-free, 24 hours a day, 7 days a week)
 - Report abuse, neglect, exploitation, or self-neglect of a dependent adult.

Signs of Elder Abuse

- Unexplained bruises or injuries
- Sudden behavior or mood changes
- Fear, anxiety, or withdrawal
- Poor hygiene or missed medications
- Unexplained financial changes
- Changes in appetite or weight
- Fear of or isolation from others
- Caregiver anger or controlling behavior

Stay Healthy and Active

Healthy habits are important for both caregivers and people living with dementia. Some ideas to stay healthy and active include:

- Exercise programs – Variety offered by Area Agencies on Aging and other local organizations
- Healthy meals options – Home delivered meals, congregate/community meals, or frozen meals offered by Area Agencies on Aging and other local providers
- Social programs – Support groups, memory cafes, and other programs may be available through your Area Agency on Aging or other local providers
- Mental & social wellbeing – Remember to take care of yourself and continue to do things you enjoy.
 - For Mental Health Resources, contact Your Life Iowa at (855) 581-8111 or www.YourLifeIowa.org

Respite Care

Respite care gives family caregivers a temporary break while their loved one is cared for safely. Regular breaks help caregivers stay healthy and continue providing care at home.

- ▶ Respite can be provided in the home, at an adult day center, or through a short stay at a care facility.
- ▶ Plan breaks regularly. You do not need to wait for a crisis to use respite.
- ▶ Ask about respite funding through your local Area Agency on Aging, Iowa Medicaid's Elderly Waiver, the VA, or Medicare's GUIDE program.

Home Safety, Wandering Support, & Dementia Friendly Design

Simple changes can be made to the home environment to make it a safer and easier place for a person with dementia.

- ▶ Consider a medical ID bracelet or necklace in case of wandering or needing help in the home
- ▶ Contact local law enforcement. Some areas may provide tracking devices or wandering response support.
- ▶ Ask doctor for an occupational therapist referral to do a home evaluation
- ▶ Learn more about Firearm Safety: <https://safetyindementia.org/firearms>
- ▶ Learn more or find home safety checklists:
 - nia.nih.gov/health/safety/alzheimers-caregiving-home-safety-tips
 - <https://alzfdn.org/theapartment/>
 - www.alz.org/help-support/caregiving/safety/home-safety

Ask About Treatment Options

While there is no cure for dementia, treatments are available. For people in the early stages of Alzheimer's disease, FDA-approved medications may slow progression, and other medications help manage symptoms at any stage. Early diagnosis matters.

- ▶ Ask your doctor which medications may be right for you or your loved one. These treatments have both risks and benefits.
 - Learn more about treatment: www.alz.org/alzheimers-dementia/treatments or call 800-272-3900
- ▶ If you are in Des Moines, Waterloo, or Dubuque, ask whether your clinic participates in GUIDE, a Medicare dementia care program offering a care navigator, a 24/7 support line, caregiver training, and a yearly respite benefit for people with traditional Medicare.
 - Learn more about the GUIDE model:
<https://www.cms.gov/priorities/innovation/innovation-models/guide>
- ▶ Ask doctor for an occupational therapist referral to do a home evaluation
- ▶ Learn more about Firearm Safety: <https://safetyindementia.org/firearms>
- ▶ Learn more or find home safety checklists:
 - nia.nih.gov/health/safety/alzheimers-caregiving-home-safety-tips
 - <https://alzfdn.org/theapartment/>
 - www.alz.org/help-support/caregiving/safety/home-safety

Find Local Support

Finding local support is important to maintain a good quality of life for both the person with dementia and the caregiver. Family caregivers are defined as anyone who is providing informal support to an older adult or person with dementia.

- ▶ The local Area Agency on Aging (AAA) can assist with connecting you with valuable local supports and resources. Services may include information & referral to local programs, benefits screening, education, coordination for in-home care & service options, and emotional support. To find your local AAA go to <https://www.iowacompass.org> or call (800) 779-2001
- ▶ Call the Alzheimer's Association at 800-272-3900 to connect with to a local support group.
- ▶ If your community has a caregiver resource center, consider getting connected.
 - The Chris & Suzy DeWolf Family Innovation Center for Aging & Dementia Located in Cedar Rapids; older adults living with chronic conditions, such as dementia, and their caregivers are empowered to lead satisfying and fulfilling lives. The center offers virtual and in-person support groups, memory cafes, engaging activities, education, one-on-one care consultations, memory health clinic, and more. Contact (319) 784-9200 or visit, <https://www.dewolfinnovationcenter.org/home/>
 - In Dubuque, the Stonehill Caregiver Resource Center is where family caregivers can access resources and support. Visit: <https://www.stonehilldbq.com/caregiverresourcecenter/> or call (563) 690-9679.

Support Groups

- ▶ Support groups are offered by AAA's and the Alzheimer's Association.
- ▶ Benefits of Joining a Support Group
 - Get Emotional Support
 - Connect with others
 - Regain a Sense of Control
 - Provide Support to Others

Other Helpful Websites/Organizations for Specific Diseases

- ▶ Lewy Body Dementia Association - www.lbda.org | 800-539-9767
- ▶ Alzheimer's Foundation of America - www.alzfdn.org | 866-232-8484
- ▶ Association for Frontotemporal Degeneration - www.theaftd.org | 866-507-7222
- ▶ Creutzfeldt-Jakob Disease Foundation - www.cjdfoundation.org | 1-800-659-1991
- ▶ Huntington's Disease Society of America - <https://hdsa.org> | 800-345-4372
- ▶ National Institute on Aging (ADEAR Center) - www.alzheimers.gov | 1-800-438-4380
- ▶ Parkinson Foundation - <https://www.parkinson.org/> | 1-800-473-4636
- ▶ The Upstreet Project - Supporting individuals with ARBD and Korsakoff's Syndrome - www.korsakoffs.org
- ▶ Concussion and CTE Foundation - <https://concussionandcte.org/> | 857-244-0810

Iowa Dementia Resource List

Alzheimer's Association

- 1-800-272-3900 | www.alz.org
- Supports people with all types of dementia, not just Alzheimer's Disease
- Hosts support groups/education for people living with dementia and caregivers
- Provides care consultations, referrals, information, and individual meetings
- Walks client through legal/financial planning, future living preferences, etc
- Local support group listing: <https://www.alz.org/iowa>

Area Agencies on Aging & Iowa Compass

- (800) 779-2001 | <https://www.iowacompass.org>
- Home & phone visits to equip client with strategies to safely age in home
- Potentially able to offer funding for homemaker, transportation, respite care, etc
- Family care consultations and referrals to other local resources; support groups

Dementia Friendly Iowa / Dementia Friends

- 319-287-1192 | www.dementiafriendlyiowa.org
- Provides education for the community about dementia (Dementia Friends and Dementia Friendly Business trainings); builds dementia friendly communities
- Seeks to make Iowa a better place for people with dementia and their caregivers
- Opportunity to volunteer as an advocate for people with dementia and community educator

Dependent Adult Protective Services

- 1-800-362-2178 (toll-free, 24 hours a day, 7 days a week)
- Report abuse, neglect, exploitation, or self-neglect of a dependent adult
- If a person is in imminent danger, call 911

Iowa Department of Health & Human Services

- **Iowa Aging Services:** hhs.iowa.gov/family-community/aging-services
Supports the Long-Term Care Ombudsman program, Managed Care Ombudsman program, Retired & Senior Volunteer Program (RSVP), Area Agencies on Aging, and more.
- **Iowa Alzheimer's and Related Dementias Program:** <https://bit.ly/HHSAlzheimersAndOtherDementias>
Public health and healthy brain initiative; educational information available. Read the State Strategic Plan for Alzheimer's Disease & Related Dementias in Iowa:
<https://hhs.iowa.gov/media/592/download?inline>

The Association for Frontotemporal Degeneration (AFTD)

- 1-866-507-7222 | <https://www.theaftd.org/iowa/>
- Specific to FTD dementia; reliable information, valuable resources, essential support, and opportunities to make a difference. Support groups available throughout the state.

The Chris & Suzy DeWolf Family Innovation Center for Aging & Dementia

- (319) 784-9200, <https://www.dewolfinnovationcenter.org/home/>
- Located in Cedar Rapids; older adults living with chronic conditions, such as dementia, and their caregivers are empowered to lead satisfying and fulfilling lives. The center offers virtual and in-person support groups, memory cafes, engaging activities, education, one-on-one care consultations, memory health clinic, and more.



Dementia Friendly Iowa works to create welcoming, safe, and respectful communities where people living with dementia and their caregivers can live and thrive. Through education, awareness, and initiatives like Dementia Friends and Dementia Friendly Communities, the program helps communities across Iowa become more informed and supportive.





Health and
Human Services



For electronic copy, use your phone's camera to scan QR code or visit
<https://dementiafriendlyiowa.org/iowa-dementia-resource-guide/>

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