

Now What?

A Guide for Young Onset Dementia Diagnosis in Wisconsin

Young onset dementia refers to any form of dementia diagnosed in people between the ages of **30 and 65 years, or even younger.**

Young onset dementia (YOD) presents unique challenges compared to later-onset dementia, as it affects people during their prime working years, while raising children, and often with different social and financial circumstances. Common types of YOD include:

- Alzheimer's Disease
- Frontotemporal Dementia (FTD)
- Vascular Dementia
- Lewy Body Dementia
- Posterior Cortical Atrophy
- Huntington's Disease and other familial/genetic forms

Learn about YOD conditions

You and your care partner need to learn what type of dementia you have (e.g., Alzheimer's disease, Lewy body dementia, frontotemporal dementia) and how it typically progresses.

☑ **Alzheimer's and related Dementias Education and Referral (ADEAR) Center** [Alzheimer's & Related Dementias](#) or call 800-438-4380

☑ **Alzheimer's Association** [If You Have Younger-Onset Alzheimer's Disease](#) or call 800-272-3900

☑ **Aging & Disability Resource Center** and ask for a referral to the Dementia Care Specialist [Aging and Disability Resource Centers \(ADRCs\) | Wisconsin Department of Health Services](#) or call 844-947-2372

☑ **Lewy Body Dementia Association** [Lewy Body Dementia Association](#) or call 800-539-9767

☑ **The Association for Frontotemporal Degeneration** [The Association for Frontotemporal Degeneration](#) or call 866-507-7222

☑ **Huntington's Disease Society of America** [Huntington's Disease Society](#) or call 800-345-4372

☑ **Rare Dementia Support** [Rare Dementia Support](#)

☑ **Video: Young Onset Dementia** https://www.youtube.com/watch?v=u4LB_3PDR_E

☑ **Consider using a Dementia Journey Journal:** [Our Dementia Journey Journal](#)

If you are working

Before your condition significantly affects your ability to do your job, talk to your human resources department or employer.

☑ Find out if you can switch to a position that better suits your emerging limitations or consider reducing your hours or taking time off.

☑ Consider consulting your employer's HR department or employee assistance program about family leave (FMLA), disability benefits, and other employee benefits.

☑ **Alzheimer's Association:** Receiving a diagnosis while working [If You Have Younger-Onset Alzheimer's Disease](#) or call 800-272-3900

☑ Checklist for applying for **Social Security Disability or Supplemental Security Income** benefits due to young onset dementia: [Checklist for Applying for Social Security Disability and Supplemental Security Income Benefits Due to Early-Onset \(Younger-Onset\) Alzheimer's Disease](#)

☑ **Agging & Disability Resource Center** and ask for a referral to the Disability Benefit Specialist [Agging and Disability Resource Centers \(ADRCs\) | Wisconsin Department of Health Services](#) or call 844-947-2372

☑ Explore what benefits may be offered to you under the **Americans with Disabilities Act** [Introduction to the Americans with Disabilities Act | ADA.gov](#) or call 800-514-0301

Do legal, financial, and long-term planning

☑ Get information to help you and your partner plan in critical areas. [Planning After a Dementia Diagnosis | Alzheimers.gov](#)

☑ Prepare or update your will, living will, health care power of attorney, and financial power of attorney. [Getting Your Affairs in Order Checklist: Documents to Prepare for the Future | National Institute on Aging](#)

[The Conversation Project](#)

☑ Planning ahead for legal matters: [Planning Ahead for Legal Matters | Alzheimer's Association](#)

☑ Financial Planning: [Financial Planning | Alzheimer's Association](#)

☑ To find a lawyer, contact your local bar association or the National Academy of Elder Law Attorneys. [I Need a Lawyer](#) or call 800-362-9082 or [National Academy of Elder Law Attorneys](#)

☑ Learn about care you may need in the future and how to pay for it. Explore getting help to pay for medicines, housing, transportation, in-home care and more by contacting your local Agging & Disability Resource Center: [Agging and Disability Resource Centers \(ADRCs\) | Wisconsin Department of Health Services](#) or call 844-947-2372

☑ If you are a veteran, check with your local Veterans Service Office for State & Federal Benefits [County and Tribal Veterans Service Officers \(CVSO/TVSO\) - Wisconsin Department of Veterans Affairs](#) or call 800-947-8387

Stay safe on the road

☑ You should talk with your doctor if you become confused, get lost, need a lot of help with directions, or if others worry about your driving.

☑ Consider a driving evaluation. Ask your doctor for names of driving evaluators.

☑ Learn about driving safety: [Driving Safety and Alzheimer's Disease | National Institute on Aging](#)

[Understanding Dementia & Driving | The Hartford Dementia & Driving | Alzheimer's Association](#)

Find services and support after diagnosis

☑ **Alzheimer's Association (all dementia):**

- Support groups, ALZNavigator, My ALZ Journey app, ALZConnected online community forum, Living Well, 24/7 Helpline 800-272-3900
[Alzheimer's & Dementia Resources](#)

☑ Contact your local **Alzheimer's Disease Research Center**: [Wisconsin Alzheimer's Disease Research Center](#) or call 608-265-0407

☑ **Lorenzo's House:** (children/youth)

- Peer support for children/youth, Virtual clubs for support, Care partner peer support:
[Lorenzo's House](#)

☑ **Young Onset Dementia Education & Support:**

<https://yessupport.org>

☑ **Aging & Disability Resource Center:**

- Memory cafes, Brain health, Support groups, Caregiver training & support, Help with difficult symptoms of dementia, Pre-crisis planning, Respite care options, Technology solutions, Help with family meetings, and Education:
[Aging and Disability Resource Centers \(ADRCs\) | Wisconsin Department of Health Services](#) or call 844-947-2372

☑ Use a care communication app to keep everyone connected and informed:

[Caring Village](#)

[Lotsa Helping Hands](#)

[CaringBridge](#)

[Connected Caregiver App - Family Care Management Tools](#)

Be safe at home and out and about

☑ **Get home safety tips:**

[Alzheimer's Association Home Safety Checklist](#)

[Dementia Enabling Environments](#)

[The Apartment: A Guide to Creating a Dementia-Friendly Home | Alzheimer's Foundation of America](#)

☑ Ask the doctor to order a home safety evaluation and recommend a home health care agency to conduct it. Check to see if health insurance will cover the cost.

☑ **Firearm Safety:**

[Firearms Safety](#)

[Create a plan to protect you, your family, and your legacy](#)

☑ Contact your local **Aging & Disability Resource Center** to learn more about public safety registries, Purple Tube, and GPS location devices: [Aging and Disability Resource Centers \(ADRCs\) | Wisconsin Department of Health Services](#) or call 844-947-2372

☑ Crisis planning, know who to call (clinic, after-hours line, trusted friends, or relatives) and have a simple plan for difficult days and if something happens to your care partner.

[EMERGENCY PLANNING WORKBOOK](#)

Maximize brain health

☑ Lifestyle Recommendations to Maximize Brain Health: [Lifestyle Recommendations to Maximize Brain Health](#)

☑ Use brain exercise apps:

[NewDays AI](#)

[AcTo Dementia](#)

[MindMate](#)

[Lumosity](#)

Understanding the family journey

☑ Helping children and adolescents when a parent has YOD:

[Lorenzo's House](#) (child/youth peer support)

[Helping children and adolescents](#)

[Dementia in my family](#)

[Explaining dementia to children and young people |](#)

[Alzheimer's Society](#)

[American Association of Caregiving Youth](#)

☑ Check specific dementia websites listed in “Learn about YOD conditions”.

☑ Helping changes to your relationships:

[Changes to Your Relationship | Alzheimer's Association](#)

[Changing relationships and roles | Dementia UK](#)

[AMBIGUOUS LOSS AND GRIEF IN DEMENTIA |](#)

Consider participating in a clinical trial

☑ Search for a clinical trial or study near you or that you could participate in remotely:

[Volunteer for a study | Alzheimer's Disease](#)

[Research Center](#)

[TrialMatch: Participate in Clinical Research for](#)

[Alzheimer's and Other Dementia](#)

☑ Learn more about clinical trials:

• NIA Clinical Trials Information

www.nia.nih.gov/health/clinical-trials

Notes