

Connecting Those Impacted by Young Onset Dementia to Essential Resources:

Practical navigational guides to use with clients.



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Collaborators

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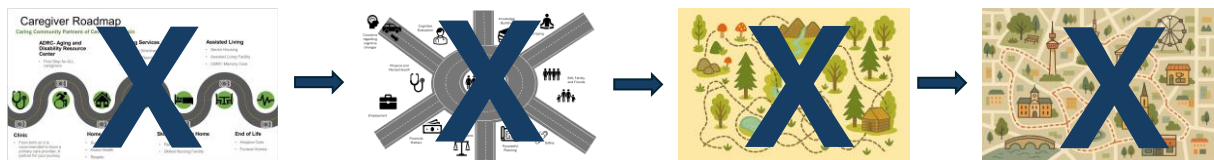
Heidi Neeley, Program Manager and Research Champion, Alzheimer's Association, Wisconsin Chapter

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Jody, Krainer, LCSW, MBA, Dementia Diagnostic Clinic Network Manager, Wisconsin Alzheimer's Institute

The initial goal of the collaboration...

Create a caregiver roadmap for families affected by younger onset.




Not linear, not one-and-done, not the same for all.

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Now What?

Next Steps After an Alzheimer's Diagnosis

A diagnosis of Alzheimer's disease 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 help you get started.



Learn about Alzheimer's disease

- Being informed will help you know what to expect as the disease progresses. Here are some resources:
 - Alzheimer's and related Dementias Education and Referral (ADEAR) Center www.alzheimers.org | 1-800-438-4388
 - Alzheimer's Association www.alz.org | 800-272-3900
 - Alzheimer's Foundation of America www.alzfdn.org | 866-232-8484
 - Local hospitals and community centers may have educational programs about Alzheimer's disease and related dementias.

Get regular medical care

- Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist). www.nia.nih.gov/health/doctor-patient-communication-talking-with-your-doctor
- Consider going to a memory disorders clinic. Ask your doctor for a referral if desired.

Find local services and support

- Find local services by contacting Eldercare Locator www.eldercare.gov | 1-800-677-1116
- Contact your local Alzheimer's Disease Research Center www.nia.nih.gov/health/alzheimers-disease-research-centers
- Find local chapters, organizations, and support groups:
 - Alzheimer's Association www.alz.org | 800-272-3900
 - Alzheimer's Foundation of America www.alzfdn.org | 866-232-8484

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

- Get information to help you plan: www.nia.nih.gov/health/legal-and-financial-planning-people-with-dementia
- Prepare or update your will, living will, health care 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.naelsa.org
- Learn about care you may need in the future and how to pay for it: www.eldercare.gov
- Explore getting help to pay for medicines, housing, transportation, and more.
- See tips about coping daily, changes in relationships, and more. www.nia.nih.gov/health/alzheimers/caring

Get help as needed with day-to-day tasks

- Use simple memory aids like a rosetta or sticky notes to list down reminders, a pillbox to keep medications organized, and a calendar to record appointments.
- Ask family members or friends or find local services to help with routine tasks, such as cooking, laundry, 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, changes in relationships, and more.

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Be safe at home

- Get home-safety tips. www.nia.nih.gov/health/home-safety-checklist
- Consider wearing a medical ID bracelet or necklace in case you get lost or need help, or joining the **MediAlert** and Alzheimer's Association's **Wandering Support** program. www.medialert.org
- Ask your doctor to order a home-safety evaluation and recommend a home health care agency to conduct it. Medicare may cover the cost.

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. www.nia.nih.gov/health/driving-safety-and-alzheimers-disease
- Get a driving evaluation. Ask your doctor for names of driving evaluators, or visit the American Occupational Therapy Association. www.occupationaltherapy.org/river_search

Consider participating in a clinical trial

- Ask your doctor about trials or studies.
- Contact an **Alzheimer's Disease Research Center** for assessment and potential research opportunities.
- Search for a clinical trial or study near you or that you could participate in remotely.
 - NIA Clinical Trials Finder www.nia.nih.gov/health/clinical-trials
 - NIA Clinical Trials Information www.nia.nih.gov/health/clinical-trials
 - National Institutes of Health www.nih.gov/health-information/nih-clinical-research-trials-you

Stay healthy

- Be active! Getting exercise helps people with Alzheimer's feel better and helps keep their muscles, joints, and heart in good shape. www.nia.nih.gov/health/exercise-physical-activity
- Eat a well-balanced diet that includes fruits, vegetables, and whole grains. www.nia.nih.gov/health/healthy-eating
- Continue to enjoy visits with family and friends, hobbies, and outings.

If you live alone

- 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.
- Consider working with an occupational therapist. This person can teach you ways to stay independent. Ask your doctor for more information.
- Stick with familiar places, people, and routines.
- Get tips about self-care, safety, staying connected, and more. www.nia.nih.gov/health/tips-living-alone-early-stage-dementia

If you are working

- If you have problems performing your job, consider reducing your hours or switching to a less demanding position.
- Consider consulting 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." www.ssa.gov/compassionateallowances 800-772-1213

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What do I do?

A Guide for Getting a Cognitive Evaluation

Experiencing cognitive changes and between the ages of 30 and 65 years, or even younger?

Are you or someone you care about experiencing any of the following symptoms and are between the ages of 30 and 65 years, or even younger?

- Trouble planning, organizing, making decisions—often noticed at work, learning new things, or adapting to a change
- Difficulty finding words or following conversations
- Personality shifts, loss of motivation, loss of interest in things you used to enjoy, loss of inhibitions, or uncharacteristic anger, short-tempered, and/or aggression
- Anxiety, irritability, or depression attributed to stress or a midlife crisis
- Disorientation in familiar locations, forgetting important work meetings, or coworkers' names
- Unexplained clumsiness, issues with balance, coordination, or judging distances
- Seeing things that are not there (hallucinations), blurred or double vision
- Having interactions with law enforcement due to recent behavior changes
- Experiencing one or more of the above symptoms, but unable to recognize it (lack insight)

The above symptoms may be associated with many different medical conditions; having a comprehensive evaluation is critical to determining what is happening. Young onset dementia (YOD) is often not on the radar for healthcare professionals or the individual experiencing changes, as it is typically associated with older adults.

What is Young Onset Dementia (YOD)?

Young onset dementia (YOD) refers to those diagnosed with dementia prior to the age of 65 years; about 5% of all those diagnosed with dementia. Dementia is a term used to describe thinking and memory issues severe enough to interfere with daily life. Alzheimer's disease is the number one cause of dementia; however, for younger individuals there are a number of other potential causes of dementia besides Alzheimer's disease, such as:

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

Determining a diagnosis of YOD can be extremely difficult, the average time from first symptoms to diagnosis is 4 years, which is 57% longer than those diagnosed with late-onset dementia. Learn more at Dementia.UK's.Young.Onset.Dementia.Different.Symptoms.Guide

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 www.alzheimers.org and Related Dementias or call 800-438-4380
- Alzheimer's Association www.alz.org 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 Center's (ADRCs) | Wisconsin Department of Health Services or call 844-947-2372
- Lewy Body Dementia Association www.lbda.org or call 800-539-9767
- The Association for Frontotemporal Degeneration www.theftd.com or call 866-507-7222
- Huntington's Disease Society of America www.hdsa.org or call 800-345-4372
- Rare Dementia Support www.rare-dementia.org
- Video: Young Onset Dementia https://www.youtube.com/watch?v=ru4LB_3FD0E
- Consider using a Dementia Journey Journal: www.dementiajourneyjournal.com

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Agenda

- What is young/younger onset dementia (YOD)?
- The gaps that inspired the guides
- The navigational guides:
 - Guide for Getting a Cognitive Evaluation
 - Guide for Young Onset Dementia Diagnosis in Wisconsin
- Questions, comments, and thoughts



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What is Dementia?

Dementia is an umbrella term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

Symptoms may include: confusion, disorientation, memory loss, language and behavior changes.



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What is Young/Younger Onset Dementia (YOD)?

Dementia diagnosed before age 65 (between the ages of 30 and 65)

Represents about 5% of all dementia cases

Common types:

- Alzheimer's disease
- Frontotemporal dementia (FTD)
- Vascular dementia
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- Traumatic Brain Injury

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Unique Challenges

- Employment impact – loss of income, career disruption
- Family dynamics – caring for children and aging parents
- Misdiagnosis risk- symptoms mistaken for stress or depression
- Social stigma – lack of awareness compared to late-onset dementia

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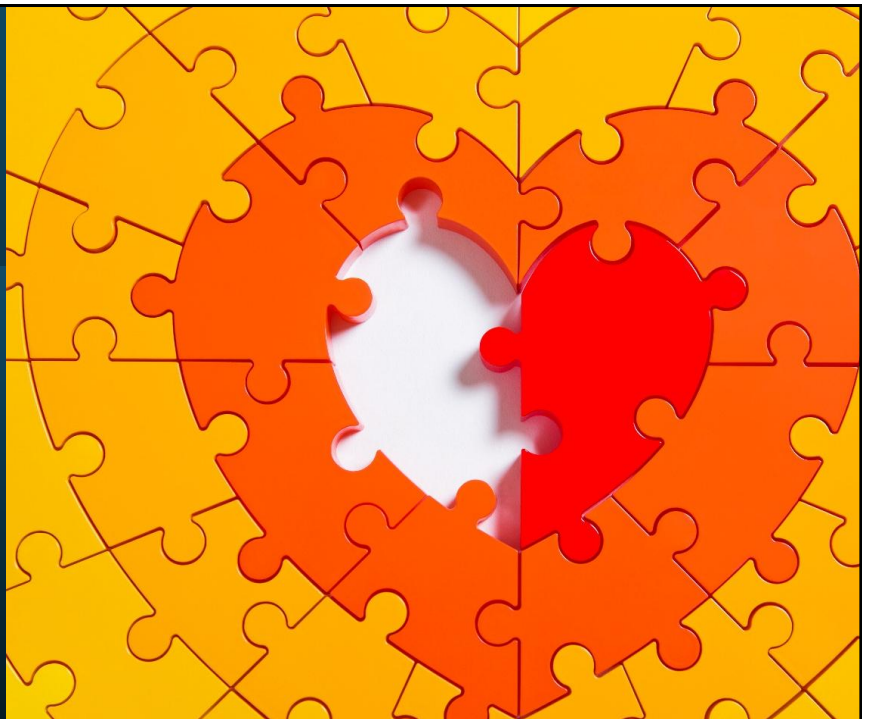
Symptoms



- Trouble planning, organizing or making decisions
- Difficulty finding words or following conversations
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- Anxiety, irritability or depression
- Disorientation in familiar locations, forgetting names or appointments
- Unexplained clumsiness, issues with balance, coordination or judging distances
- Seeing things that aren't there, blurred or double vision
- Interactions with law enforcement due to behavior changes
- Memory changes?
- Experiencing one or more of the above symptoms, but unable to recognize it (lack of insight)

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The Gaps that
Inspired the
Guides



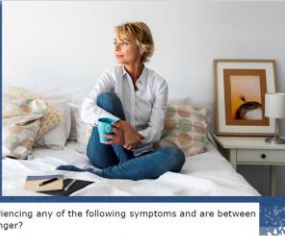
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Guide for Getting a Cognitive Evaluation

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- Rationale behind the companion guide
- Sections
 - Symptom identification
 - What is Young Onset Dementia (YOD)?
 - Why Getting a YOD Diagnosis is Difficult
 - Steps to Take
 - Key Tips
- Heavy on text in effort to build insight and knowledge
- Document links:
 - YOD symptoms guide
 - Symptom checklists
 - WAI memory clinics
 - Wisconsin ADRCs
- Updated annually, version date will be on last page

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Guide for Young Onset Dementia Diagnosis in Wisconsin

Now What?

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📄 [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 866-907-7222

📄 [Huntington's Disease Society of America](#) [Huntington's Disease Society of America](#) 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](#)

- Rationale behind the companion guide
- Sections
 - Learn about younger onset dementia conditions
 - If you are working
 - Do legal, financial, and long-term planning
 - Stay safe on the road
 - Find services and support after diagnosis
 - Be safe at home and out and about
 - Maximize brain health
 - Understanding the family journey
 - Consider participating in a clinical trial
- Feedback from 2 support groups of spouses/family members of PLW YOD

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Understanding the family journey

- Helping children and adolescents when a parent has young onset dementia: [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 young onset dementia 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

ADRC Aging and Disability Resource Center

ALZHEIMER'S ASSOCIATION Wisconsin Chapter

Wisconsin Alzheimer's Institute UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH

January 2026

- Document links:
 - Specific dementia websites; rare dementia
 - Disability specific resources while working
 - Added Veteran Service Officers
 - Lorenzo's House
 - Added family communication apps
 - Home safety
 - Firearm safety
 - Emergency planning
 - Added brain health exercise apps
 - Support for children/youth
 - Ambiguous loss/grief
 - Wisconsin Alzheimer's Association
 - Aging & Disability Resource Centers
 - Alzheimer's Disease Research Center

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Questions, comments, and thoughts.

Are you aware of other resources?
For example, for family members,

Younger Onset Support Group- Stoughton, WI
When: 1st Wednesdays 6:00-7:30pm
Where: Abundant Health Chiropractic
318 S Water Street, Stoughton, WI 53589
Contact: Heidi Neeley 608-340-1499
hhneeley@alz.org

Younger Onset Support Group – Waukesha, WI
When: 2nd Wednesdays 3:00-4:30 pm
Where: ADRC of Waukesha County
514 Riverview Ave, Waukesha, WI 53188
Contact: Jennifer Harders 262-548-7650
jharders@waukeshacounty.gov

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ALZHEIMER'S ASSOCIATION Wisconsin Chapter



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