

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](#)

Why Getting a Young Onset Dementia Diagnosis is Difficult

1. Professional and Clinical Barriers

- **Low Clinical Suspicion:** Dementia is traditionally associated with old age; healthcare providers often do not consider it for patients in their 40s or 50s. Many doctors are not confident in recognizing rarer subtypes common in YOD, such as frontotemporal dementia (FTD) or posterior cortical atrophy.
- **Misdiagnosis as Psychiatric Issues:** Symptoms like personality shifts, apathy, and social withdrawal are frequently misdiagnosed as depression, anxiety, or bipolar disorder.
- **Atypical Symptoms:** Younger individuals are less likely to present with memory loss and more likely to show changes in language, vision, or behavior, making the condition harder for non-specialists to recognize.

2. Personal and Social Barriers

- **Denial and Fear:** Patients, spouses, and other family members may be reluctant to face the possibility of a dementia diagnosis due to the terminal nature and the profound impact on their future.
- **Stigma:** Younger patients often feel a powerful sense of social stigma, perceiving dementia as an "old person's disease" or a "mental illness," which leads them to hide or normalize symptoms.
- **Normalization of Symptoms:** Early signs are often dismissed as "mid-life" issues such as work-related stress, burnout, major life events (divorce, death of a parent), or menopause.

3. Systemic and Diagnostic Challenges

- **Lack of Specialized Services:** Standard memory clinics are often designed for the elderly and may use screening tools that are not sensitive enough to detect the complex presentations of YOD.
- **Access Barriers:** Getting appointments with the necessary specialists (neurologists, neuropsychologists) often requires multiple referrals and long wait times between appointments, which increases patient anxiety and diagnostic delay.
- **Geographical and Economic Gaps:** Those in rural areas or lower socioeconomic backgrounds face higher barriers, including longer travel distances to specialist clinics and lack of insurance coverage for advanced tests like amyloid PET scans.

Steps to Take

To be evaluated for YOD effectively, you must navigate a process that often requires persistent self-advocacy and specialized testing. Because the condition is rare in younger adults, standard primary care screenings may be insufficient.

1. Prepare Your Evidence

Before your first appointment, gather "collateral history"—detailed observations from family or friends—to provide a full picture of changes.

- **Keep a Symptom Journal:** Record specific examples of changes in memory, behavior, language, or vision, noting dates and how they impact your daily work or home life.
- **Use Checklists:** Capture your symptoms using specialized tools like the [Alzheimer's Society Canada's Signs and Symptoms of Young Onset Dementia](#) checklist or the [Young Dementia Network's Signs and Symptoms of Young Onset Dementia: A Personal Checklist](#).

2. Start with a Comprehensive Medical Exam

Visit your primary care provider (PCP) to rule out "reversible" causes of cognitive decline, such as vitamin B12 deficiencies, thyroid issues, sleep apnea, or infections.

- **Request Specific Lab Work:** Ask for blood tests that screen for these treatable conditions.
- **Insist on Referrals:** If basic tests are normal but symptoms persist, request a referral to a specialist. Remind your provider that younger people **can** develop dementia and that standard tests like the MMSE or MoCA may not detect early YOD.

3. Consult Specialized Experts

YOD often requires a multidisciplinary team rather than a single doctor.

- **Neurologist:** Specializes in brain and nervous system disorders.
- **Neuropsychologist:** Conducts in-depth cognitive testing to evaluate executive function, language, and behavior.
- **Memory Disorders Centers:** Seek out academic medical centers or specialized clinics that have dedicated programs for younger adults, such as those in the WAI Dementia Diagnostic Clinic Network: <https://wai.wisc.edu/memory-clinic-network-list/>. You can also contact your Aging & Disability Resource Center by calling 844-947-2372 or visiting <https://www.dhs.wisconsin.gov/adrc/category/dementia-and-memory-loss>

4. Advanced Diagnostic Testing

Specialists may use advanced biomarker tests to confirm the biology of the disease:

- **Brain Imaging:** MRI or CT scans rule out structural issues (like tumors), while **PET scans** (Amyloid or FDG) can detect specific protein plaques or changes in brain activity.
- **Cerebrospinal Fluid (CSF) Analysis:** A lumbar puncture (spinal tap) can detect protein markers (beta-amyloid and tau) with high accuracy.
- **Blood Biomarker Tests:** As of 2026, newer FDA-cleared blood tests are increasingly used in specialty clinics to aid in earlier, less invasive diagnosis.
- **Genetic Counseling:** If you have a strong family history, consult a genetic counselor to discuss testing for inherited mutations.

Key Tips

- Be persistent—diagnosis often requires multiple appointments.
- Bring written evidence and advocate for specialized testing.
- Connect with support organizations early for guidance and emotional support.