



SUPPORTING CAREGIVERS IN YOUNG ONSET DEMENTIA: PRACTICAL STRATEGIES

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Getting to an Accurate Diagnosis

- Clinicians and families are not primed to consider dementia in someone who is still working, raising kids, or “too young” for it.
- Expect misattribution to mental health or life stress first.



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Practical Strategies:

Validation

- Validate the caregiver's instinct that something is wrong.
- Even when initial tests look normal or a clinician suggests it's psychiatric or stress-related.

Advocacy

- Encourage caregiver to document changes concretely and longitudinally.
- Insist on a specialist workup and more specialized testing.
- Connect to YOD-specific resources
- MoCA screening

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Barriers:

CAUTION

- Difficult to gain information from a person's employer.
- Standard counseling advice may conflict with YOD realities.
- Diagnosis may change.
- Crisis may show up first!
 - Law enforcement
 - Loss of job
 - Child safety
 - Loss of money

Caregiver may be helping to care for aging parent(s) and/or children.

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After the Diagnosis: Now What?

- Help caregivers prioritize:
 - Separate urgent-safety items from important-but-not-yet items.
 - Name the caregiver's own capacity as a legitimate constraint, not a moral failing.
 - Identify what can be delegated or automated now, before a crisis forces it.
 - Flag decision fatigue explicitly.
 - Encourage them to accept "good enough" over optimal.
 - Care for themselves.

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Use Motivational Interviewing

- Reflective listening over advice-giving.
- Elicit-Provide-Elicit.
- Roll with resistance rather than arguing.
- Affirm competence explicitly.
- Use scaling questions.
- Acknowledge ambiguous loss.



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Connecting to Resources

- Local Aging & Disability Resource Center:
 - Ask for a referral to a dementia care specialist.
 - Disability benefits specialist
 - Information & Assistance specialist to explore options, caregiver grants, support groups, and eligibility for publicly funded long term care programs.
 - Advanced directives!
 - YOD specific resources (AFTD, LBDA, Lorenzo's House, etc.)
 - Workplace accommodations & family dynamics.
- Caution: Many resources, programs, and services targeted towards older adults. Get creative!

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Use the WDRN Guides:

The image shows two side-by-side guides from the Wisconsin Dementia Resource Network (WDRN). The left guide, titled 'What do I do? A Guide for Getting a Cognitive Evaluation', features a photo of a person sitting on a couch and lists various symptoms and steps for seeking evaluation. The right guide, titled 'Now What? A Guide for Young Onset Dementia Diagnosis in Wisconsin', features a photo of a family and lists resources for diagnosis and support, including support groups and educational materials.

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Thank You!

- Find your local ADRC:
 - <https://www.dhs.wisconsin.gov/adrc/contacts.htm>
- WDRN Resource Library:
 - What do I do? A Guide for Getting a Cognitive Evaluation
 - Now What? Guide for Young Onset Diagnosis in Wisconsin
 - <https://wai.wisc.edu/wdrn/wdrn-resource-library/>

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