



Navigating the Dementia Diagnosis Conversation

A Guide for Healthcare Professionals

Qr8⁺ | HEALTH

The Challenges of Discussing Dementia with Patients

Delivering a dementia diagnosis requires both skill and sensitivity, yet many physicians are uncomfortable initiating these conversations. In a **recent report**, 82% of Primary Care Physicians (PCPs) acknowledged their pivotal role on the front lines of dementia care, but not all felt adequately equipped to handle the complexities of Alzheimer's and other dementias. Nearly two in five PCPs admit to feeling "never" or only "sometimes comfortable" making a cognitive impairment diagnosis, while almost a third expressed similar discomfort in responding to patient inquiries about these conditions.

Even more concerning, 22% of PCPs received no formal residency training in dementia diagnosis and care, contributing to many feeling ill-prepared to address these issues with their patients. Of those who did receive training, a considerable 65% reported that the amount was "very little." In total, 87% have little or no training in this area.



82% of doctors recognize the importance of dementia care.

87% say they have little or no training.

In 2022, the **National Library of Medicine's National Center for Biotechnology Information** outlined clinician-level obstacles hindering effective communication of dementia diagnoses. These included:

- Low confidence in diagnosing dementia
- Reluctance to provide a diagnosis without certainty
- Challenges conveying prognostic information due to the disease's unpredictable course
- Insufficient training in communication skills for delivering diagnoses

- Perceived limited benefit of diagnosing dementia in the absence of effective treatments
- Concerns about adverse patient or family reactions, such as emotional distress or resistance
- Fears of perpetuating stigma associated with dementia

Addressing these barriers is essential to improving dementia diagnosis and care. What follows is a guide to empower healthcare providers to navigate these conversations with compassion, confidence, and clarity.

The Importance of Baseline Assessment

Initiating the dementia diagnosis journey with a baseline cognitive assessment is essential for both physicians and patients. This assessment captures the patient's cognitive status at a specific point, serving as a reference for tracking changes and early indications of disease. It provides valuable insights into cognitive strengths and weaknesses, informing personalized care plans tailored to each patient's unique needs.

These assessments facilitate communication and collaboration among multidisciplinary care teams, ensuring seamless continuity of care. They can also reassure the "worried well" that their cognitive performance is within the normal range for those within their cohort. *Read more about how to differentiate cognitive decline from normal aging.*

Incorporating discussions about cognitive health into routine healthcare conversations helps normalize the topic, emphasizing its importance as a component of overall well-being. Treating cognitive assessments as a standard component of whole-body health evaluations reduces stigma, promotes early detection, and encourages proactive management of cognitive function.

Ultimately, investing in baseline assessments establishes the groundwork for comprehensive, patient-centered dementia care that is evidence-based and responsive to evolving patient and caregiver needs.

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Discussing Memory Changes with Patients and Their Families

Clear and compassionate communication lays the groundwork for trust and collaboration throughout the care journey for both patients and their families. By actively listening and tailoring communication to the patient's individual needs and cognitive abilities, healthcare professionals can ensure the patient understands the information provided and feels actively involved in the care plan. This collaborative approach fosters a sense of agency for the patient, allowing them to participate meaningfully in decisions regarding their future health and well-being.

Researchers have **identified seven best practices** to help guide physicians:



Diagram based on *Best Practices for Communicating a Diagnosis of Dementia: Results of a Multi-Stakeholder Modified Delphi Consensus Process*, Armstrong et al.

But How Do You Start the Conversation?

Selecting the right words to initiate a conversation with patients and their families can ease the process for everyone. While each healthcare provider's approach to this difficult discussion varies, suggested best practices have been identified by a team led by Dr. Melissa Armstrong at the University of Florida School of Medicine.

Key among these practices is to begin discussions by understanding the preferences for how the diagnosis should be disclosed. While some patients may prefer a less detailed explanation, others may desire more comprehensive information. Personal values, beliefs, cultural background, and past experiences with healthcare can all play significant roles. Additionally, the severity of symptoms, emotional readiness to accept the diagnosis, and

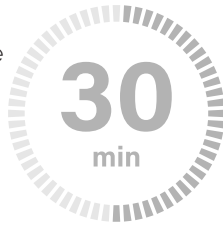
individual coping mechanisms may influence whether a patient prefers a less detailed or more comprehensive explanation.

Understanding these preferences allows you to tailor communication, ensuring that patients receive information in a manner that best suits their needs and expectations. **It's imperative, however, to avoid assuming that patients are reluctant—or incapable—of participating in open conversations about their condition.** Such assumptions can hinder effective communication, reduce patient engagement, and ultimately compromise the quality of care provided.

Once you determine the patient's preferences, here are some possible conversation starters to address the diagnosis.

APPROACH	CONVERSATION STARTER
Open the door for the patient and family to share their concerns without directly mentioning dementia.	I've noticed some changes in [your/patient's name]'s cognitive abilities during our recent visits. To understand these changes better, could you tell me a bit about how you've observed [your/patient's name]'s memory, thinking, or daily activities at home?
Acknowledge collaboration and allow the patient and family to raise their own questions.	We've been monitoring [your/patient's name]'s cognitive health, and I wanted to discuss some observations we've made. Would you be open to discussing any concerns you may have about [your/patient's name]'s memory or thinking abilities?
Emphasize routine care and focus on specific aspects of potential dementia symptoms.	As part of routine care, we sometimes assess cognitive function. Is there anything you've noticed about [your/patient's name]'s ability to remember things, make decisions, or complete daily tasks that concerns you?
Build on previous discussions and acknowledge the ongoing nature of the assessment.	During our last visit, we discussed some changes in [your/patient's name]'s memory. I'd like to follow up and see if you've observed any additional changes or have any questions about these observations.
Focus on aging and avoid using potentially stigmatizing language in the initial conversation.	Sometimes, as we age, changes in thinking and memory can occur. To ensure we're providing the best possible care, I'd like to explore these changes further with you. Is there anything specific you've noticed?
Acknowledge the diagnosis while creating a supportive environment for discussion and collaboration.	The cognitive function test you underwent recently indicates symptoms consistent with dementia. It's important to me that you feel supported and have the chance to voice any questions or concerns you may have about your diagnosis.

According to the American College of Physicians Foundation, at least 30 minutes should be allotted to disclose an Alzheimer's diagnosis. This provides time to:



- review clinical findings thoroughly
- answer questions
- discuss both nonpharmacological and pharmacological strategies
- provide some resources that will help to guide next steps.

When talking about cognitive impairment and the path forward, it most important to show empathy and compassion, understanding the emotional impact that such a diagnosis can have on both patients and caregivers. While the disease is progressive, there are opportunities for patients to maintain a good quality of life. Therefore, it is also essential to offer realistic hope by:

- ensuring that everyone understand the diagnosis and available options
- explaining that many individuals can delay the condition with simple interventions like diet, exercise, medication, and therapy.

By fostering an open environment for dialogue, you can help patients and caregivers better cope with a dementia diagnosis and navigate the journey ahead with greater understanding and support.



Next Steps After a Dementia Diagnosis Conversation

After discussing a dementia diagnosis with a patient and his or her caregiver, the next steps should include:

- 1 DEVELOP A CARE PLAN**
Outline a personalized care plan that includes medication management, regular cognitive assessments, and treatment options to slow disease progression and enhance daily functioning.
- 2 ENCOURAGE LIFESTYLE CHANGES**
Advise on positive lifestyle changes, such as regular exercise, a balanced diet, and mental stimulation, to maintain cognitive health.
- 3 BUILD A SUPPORT NETWORK**
Connect the patient and caregiver with support groups, counseling services, and community resources to provide emotional and practical support.
- 4 CREATE A MULTIDISCIPLINARY CARE TEAM**
Assemble a team of healthcare professionals, including neurologists, occupational therapists, social workers, and physical therapists, to address the comprehensive needs of the patient as the disease progresses.
- 5 PLAN FOR THE FUTURE**
Discuss long-term care options, legal and financial planning, and advanced directives to ensure the patient's wishes are respected and to ease future decision-making.

These steps can provide comprehensive care and support, helping the newly diagnosed patient and his or her family navigate the challenges of dementia with dignity and compassion.

Summary Checklist

- Use a private location with sufficient time (>30 minutes) and no distractions
- Provide culturally sensitive care and use appropriate language
- Use proper terminology for the diagnosis, such as Alzheimer's disease or Lewy body dementia
- Emphasize the current capabilities of the person with dementia and discuss the benefits of healthy lifestyle changes
- Emphasize the pros and cons of medications; emphasize non-pharmacological care approaches
- Serve as an advocate, establishing a collaborative healthcare team and providing encouragement, referrals, and resources
- Schedule follow-up visits every three months or as needed

Conclusion

Effective communication of a dementia diagnosis requires skill, sensitivity, and a well-rounded approach that addresses the needs of patients and their families. Clear and compassionate communication is key to building trust and collaboration throughout the care journey. By actively listening and tailoring conversations to individual needs, healthcare professionals can ensure that newly diagnosed patients and their caregivers feel supported and involved in the care process.

Creating an open environment for dialogue and offering realistic hope helps patients and caregivers better cope with the diagnosis and navigate the journey with greater understanding and support. This approach not only eases the emotional burden but also empowers patients to participate meaningfully in decisions about their care and future health. Providing continuous support, practical strategies, and access to resources ensures comprehensive care and enhances the quality of life for those affected by dementia.

Ultimately, a thoughtful and empathetic approach to communicating a dementia diagnosis fosters a sense of agency and collaboration, making the challenging journey more manageable for patients and their families.



Additional Resources and Reading

[Assessing Cognitive Impairment in Older Patients](#) National Institute on Aging
[Disclosing an Alzheimer's Diagnosis Video](#) by The American College of Physicians Foundation and Alzheimer's Association
[Clinician Approaches to Communicating a Dementia Diagnosis: An Interview Study](#)
[On Telling the Truth to Patients with Dementia](#)
[HRSA, Train Health Care Workers About Dementia](#)



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About Qr8 Health

Qr8 Health is a digital health company pioneering the use of patient self-administered, clinically-validated digital outcome assessment tools for the measurement of neurological and motor function. Our vision is to enable transformational improvement in patient care by providing digital health tools for collecting highly standardized clinical data in any medical or home setting where it has not been possible or practical before.

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