

Disclosing a diagnosis of dementia

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Clinical question

What is the best way to disclose a dementia diagnosis?

Bottom line

Dementia is a diagnosis almost everybody fears. For many physicians, sharing the diagnosis is one of the hardest parts of dementia care. Research suggests we do not always do this important task well; patients identify concerns about reticence to provide a precise diagnosis or explain the diagnosis and prognosis; insensitive or abrupt manner; limited opportunities to address emotional needs of the person with dementia (PWD) and caregivers; limited discussion of treatments; and lack of follow-up and support.¹

Canadian guidelines say the issue is not “whether or not to disclose the diagnosis of dementia but rather how and when to do so.”² A structured approach can help alleviate physician anxiety and improve the experience of the PWD and caregivers. Most important, disclosure is not a single event but a dynamic, evolving process including prediscovery preparation, sensitive individualized disclosure, and follow-up education and support. A comprehensive review of this approach can be found in the *CGS Journal of CME*.³

Evidence

Early diagnosis is associated with improved outcomes such as reduced caregiver stress, delayed transition into long-term care, and decreased responsive behaviour.⁴ Well planned, timely diagnosis has potential benefits for management, including increased trust, adherence to care recommendations, and understanding of disease processes, and earlier advance care planning. Early referral to community supports (eg, the Alzheimer Society) improves outcomes and might assist FPs with education and management.⁵

Approach

When disclosing the diagnosis, best practice involves preparing, exploring patient perspectives, integrating family, sharing the diagnosis, communicating effectively, responding to patient reactions, focusing on quality of life, and planning for the future.⁶ Be clear and use the word *dementia* when appropriate rather than euphemisms such as *cognitive changes* or the new DSM-5 term *neurocognitive disorder*, which might not be understood. If family members wish to shield the patient from the diagnosis, the FP should explore the underlying factors; in most cases disclosure to the patient is the best approach.⁷

People fear dementia; be clear on the expected rate of decline and prognosis, especially early on. In many cases, this rate is slower than patients expect. It is helpful for PWDs to know their FPs will not abandon them and will work with them to guide decisions and provide support as the illness progresses.⁸ Monitor PWDs and caregivers for anxiety, depression, and isolation from the time of disclosure. Responding to patient and caregiver emotions and fostering a sense of hope⁹ and meaning are important. Take a person-centred approach that maintains the PWD's personal integrity and instills hope as appropriate.^{7,10}

Implementation

The FP is the clinician most likely to disclose dementia and the main provider of ongoing care. A well-done disclosure can be key for PWDs and caregivers in the short and long term. The diagnosis can move the PWD to a highly stigmatized social group; FPs can help reduce shame, rejection, isolation, loss of control, altered self-image, apathy, and social withdrawal by viewing the disclosure as an opportunity.⁸ Robert Buckman wrote, “The task of breaking bad news is a testing ground for the entire range of our professional skills and abilities. If we do it badly, the patients or family members may never forgive us; if we do it well, they will never forget us.”¹¹ This is certainly true with dementia disclosure. 🌿

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Competing interests
None declared

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