

DISCLOSING A DIAGNOSIS OF DEMENTIA: RECOMMENDATIONS FOR A PERSON-CENTRED APPROACH



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Background

With the rise in the prevalence of dementia and its critical impact on health care resources, there has been a global call for a more proactive approach to the care of persons with dementia (PWDs), with a special focus on the practices of primary care physicians (PCPs).¹⁻³ This renewed interest has resulted in a proliferation of international consensus position papers and clinical practice guidelines (CPGs) reaffirming the importance of timely and responsive *primary dementia care*.¹⁻⁴ For a multitude of ethical, clinical, and psycho-social reasons, CPGs advocate for an early diagnosis and effective diagnostic disclosure as the first steps in the optimal management of dementia.¹⁻¹⁰ It is believed that an informative and sensitive diagnostic disclosure can provide an opportunity for PWDs and their caregivers to more proactively participate in their treatment/management plans and better adjust to the illness, both emotionally and practically, even though they may be initially distressed by the bad news (Table 1).

However, the evidence from several international studies and review papers shows wide variability in the attitudes and practices of PCPs vis-à-vis all dimensions of dementia diagnostic disclosure.^{6,7,9-14} Many PCPs withhold the diagnosis in a significant number of cases, and they fail to properly follow up with PWDs and caregivers. Furthermore, the manner and content of the diagnostic disclosure are often incongruent with the best practice recommendations and/or the expectations of PWDs/caregivers.^{9,11,13-16} The studies that have targeted PWDs/caregivers have identified the following aspects of the disclosure practices as the main sources of their dissatisfaction: (1) the physicians' reticence to make a precise diagnosis and/or to explain the diagnosis/prognosis; (2) the insensitive and abrupt manner of disclosure; (3) the limited opportunities provided to address the emotional needs of PWDs/caregivers in order to deal with the diagnosis; (4) the inadequate discussion of treatment/management options; and, finally, (5) the lack of post-diagnosis follow-up.^{11,12,14,16} Many PCPs admit having difficulty disclosing a

diagnosis of dementia, particularly to the patient, and identify communication about the diagnosis as one of the most difficult aspects of dementia care.^{9,11,13} There is evidence that physicians' hesitations are, at least partly, underpinned by their (1) uncertainties about the diagnostic accuracy; (2) assumptions about the inability of PWDs to understand/retain the diagnosis; (3) desire to protect the PWDs/caregivers from the emotional distress of receiving a highly feared and stigmatized diagnosis; (4) a lack of time and communication skills to effectively break the news; (5) nihilistic attitudes about the therapeutic benefits of interventions; and (6) an anticipation of adverse reactions to the diagnosis and the risk of damaging the longstanding doctor-patient-family relationship.^{7,9-11,13,15,17} This discomfort is reflected in a number of physician behaviours during the diagnostic disclosure aimed at "dulling" the news and downgrading its negative connotation, including the common use of euphemistic and vague terms (e.g., "confusion" and "memory problems") to avoid a frank discussion of the specific medical diagnosis, incomplete disclosure (especially, withholding information about the likely prognosis), and the use of diversion tactics (e.g., changing the subject, premature reassurance, quick wrap-up of conversation, etc.).^{7,9-11,13,15,17} Recognizing the complexity of dementia diagnostic disclosure, many experts have advocated for physician training in effective disclosure practices, as well as the development of detailed, practical, and evidence-based guidelines to promote appropriate behaviours.^{7,10,12,15,18} The goal of this article is to provide practical recommendations for a person-centred approach to dementia diagnostic disclosure in order to help PCPs better prepare for and manage this critical encounter with their PWDs and their caregivers.

Recommendations

There is a general consensus that optimal disclosure of a diagnosis of dementia is not a one-time event but, rather, an evolving and dynamic process involving (1) pre-disclosure evaluation and preparation, (2) timely, individualized, honest, and

Table 1. Potential Benefits of Timely Dementia Diagnostic Disclosure

PWD and Caregiver	Primary Care Physician	Society
Reduced uncertainty (explanation of symptoms)	Reduced uncertainty (explanation of symptoms)	Respect for individual right to autonomy
Enhanced choice and autonomy for PWD; possibility of developing positive coping strategies for PWD/caregiver; shared management with physician	Shared management with patient/caregiver	
Trust building in patient-caregiver-physician relationship	Trust building in patient-caregiver-physician relationship	
Better understanding of disease and management options/improved adherence with care recommendations	Creates opportunity for patient/caregiver education and improved adherence to recommendations	Improved clinical and quality of life outcomes
Timely access to specialists/support services	Timely referral/liaison with specialist /support services	
Optimal benefits of early treatment/management	Optimal benefits of early treatment/management	
Advance care planning	Advance care planning	Advance resource planning
Prevention/delay of complications/crises (e.g., accidents, disability, hospitalization, institutionalization, caregiver burden)	Prevention/delay of complications/crises (e.g., intensive and urgent crisis interventions)	Prevention/delay of complications (e.g., use of emergency department or other hospital and long-term care institutional services; increased cost of care; risk of driving accidents and other public safety concerns)
Participation in research	Recruitment for research	Advancement of research

PWD = person with dementia.

Source: Elements of this table were adapted from Hogan et al.,¹ Carpenter and Dave,⁹ Karnieli-Miller et al.,¹⁰ Bamford et al.,¹¹ and Wilkinson and Milne.¹⁴

Table 2. Pre-disclosure Preparation

Rapport Development and Perception Exploration
Engage:
<ul style="list-style-type: none"> • Build a trusting rapport with PWD/caregiver(s) • Explore their knowledge/beliefs about symptoms • Learn about their wishes/preferences
Respect autonomy: ensure meaningful involvement of PWD by asking questions such as:
<ul style="list-style-type: none"> • What do you think the change in your memory and thinking is due to? • What do you suspect the results of our testing may show? • Even if it is bad news, do you wish to know your diagnosis? • Do you wish to be told what we have found from our testing in order to discuss possible treatments?
Negotiate: ensure integration of both PWD and trusted family caregiver in process
Insight Development
Initiate discussion: begin a step-by-step discussion of diagnostic possibilities
Establish dialogue:
<ul style="list-style-type: none"> • Explore discrepancies in knowledge • Reduce gaps in understanding
Titrate information: consider background, level of knowledge, cognitive ability, and emotional readiness
PWD = person with dementia.

sensitive disclosure, and (3) post-disclosure follow-up educational and supportive interventions.^{1,6,15} This proactive, progressive, flexible, and comprehensive approach can effectively address many of the above concerns raised by PCPs. Although the process can be seen as being time consuming, given the time restrictions in a busy primary care practice, if well planned and structured, it can ultimately help avoid major communication challenges, minimize many of the distresses associated with a dementia diagnostic disclosure, and most likely improve adherence with recommendations. A sensitive and informative disclosure by a PCP can help reduce suffering and facilitate emotional healing, as a PWD and his or her caregivers come to terms with this illness.

In a recent comprehensive study, using multiple methods of inquiry (including a review of literature, interviews with PWDs/caregivers, and an expert consensus process), eight categories of appropriate dementia

diagnostic disclosure behaviours were identified: preparing for disclosure, exploring the patient’s perspective, integrating family members, disclosing the diagnosis, communicating effectively, responding to patient reactions, focusing on quality of life, and planning for the future.⁶ These categories were later endorsed by a number of CPGs, including a Canadian publication summarizing the recommendations of the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia.¹ We have incorporated these behaviours in our recommendations outlined below under the two broad subheadings of pre-disclosure preparation, and diagnostic disclosure and follow-up.

Pre-disclosure Preparation

Although, in the vast majority of cases, the ultimate goal of a diagnostic disclosure is to fully discuss the most accurate and medically specific diagnostic information available, a person-centred approach requires that the process be tailored to the abilities, preferences, and psycho-social resources of PWDs/caregivers. Thus, it is critically important that the planning process begins as soon as a dementia diagnosis is suspected. The diagnosis typically requires a comprehensive assessment conducted over a number of visits in order to complete a thorough clinical evaluation (i.e., brief cognitive testing, physical examination, medication review, etc.), basic laboratory tests, and any required neuroimaging, as appropriate. This time can also be used to evaluate the best manner of disclosure and to gradually prepare the PWD/caregiver for the eventual diagnosis. In most cases, a progressive disclosure with an upfront discussion of the possibilities is the most effective approach.^{5,12,15,19} Titrating the information can help ease the patient and caregiver into bad news (especially if they do not suspect dementia) and minimize the risks of adverse reactions (Table 2).

Although most PWDs desire that their physicians tell them the truth about their diagnosis, in exceptional cases, an involved family caregiver may object to a full disclosure of a diagnosis of dementia to the patient.^{5,9,11,14,19} This may be due to the desire of the family members to

Table 3. Diagnostic Disclosure: Meeting Information Needs

Maximize Comprehension
Provide sufficient time, a private and comfortable physical setup for meeting
Talk directly with PWD, using appropriate language (based on pre-disclosure evaluation)
Speak slowly and clearly, using simple words and short sentences
Avoid use of medical jargon, and explain any technical terminology
Give information step by step, checking understanding
Allow time to absorb information and to react to it
Elicit and address any questions or concerns
Listen attentively (pay attention to non-verbal cues) to understand meanings of diagnosis to PWD and caregiver and address any preconceptions/misconceptions
Use written material to convey key messages (see below)
Give opportunities to continue the conversation in follow-up appointments (if possible, give option of having separate follow-up meetings with PWD/caregiver to discuss personal needs/concerns)
Provide Comprehensive Information
Give the most accurate diagnosis (have a frank discussion of any uncertainties)
Make a distinction between normal aging and dementia
Explain anticipated progression of disease and its impact – i.e., what to expect from diagnosis in light of the person's general state of health, current symptoms, dementia subtype, etc. – emphasizing that prognosis is individualized, with important variations in illness manifestation
Provide a balanced view of results, pointing out the person's strengths and limitations: "The testing suggests that much of your brain is still working very well. Some areas, though, might not be quite as they were 20 years ago, and that can explain some of the memory problems you are experiencing."
Pay attention to and balance differing information needs of PWD and caregiver (be aware of communication issues that may arise in triadic medical encounters; be careful not to marginalize PWD and/or collude with caregiver)
Educate about vulnerabilities of PWD, risk of delirium/depression, and preventive measures (e.g., pharmacist to verify new medications; watch for signs of infection, delirium, depression, etc.)
Discuss therapeutic options available such as: <ul style="list-style-type: none"> • Pharmacological treatments and their potential risks and side effects • Non-pharmacological management approaches: cognitive stimulation, home/driving safety interventions, financial/legal planning, use of educational/psycho-social support services, etc.
Provide information on how to access available community resources, including how to contact a local Alzheimer Society (http://www.alzheimer.ca/en/on/ContactUs).
Plan for Post-Disclosure Follow-Up
Schedule a follow-up session to further clarify and reinforce information and to cover any topics that could not be adequately addressed: a thorough discussion of care management and safety issues (e.g., medication use, fitness to drive, home safety, risk of getting lost, risk of financial abuse, etc.)
Explore views regarding personal goals and priorities to help develop a mutually agreeable early treatment/management plan (encourage active engagement in disease management, while respecting the need to defer important decisions to future follow-up visits)
If possible, provide an information package and encourage its review in preparation for follow-up sessions, including: <ul style="list-style-type: none"> • A written summary of key issues discussed: diagnosis, initial plan of action, referrals made to services, follow-up appointments, etc. • Fact sheets, drawings, and other user friendly educational materials: i.e., information on disease, driving safety, housing options, advance directives, etc. (see the websites of an Alzheimer Society and dementia networks for more information on resources, e.g., http://www.alzheimer.ca/en/on/ContactUs and http://www.champlaindementianetwork.org/en-resources.asp)
Provide linkage to appropriate community support services for education and support
PWD = person with dementia.

protect the PWD from the reality of a dementia diagnosis, their reluctance to deal with the person's possible grief reaction, and/or their own difficulty facing the diagnosis.^{8,19} While the underlying reasons for a family's reservations should be explored, members need to be informed about the long-term benefits of an honest and sensitive disclosure to both the PWD and caregivers (see Table 1). In many cases, the concerns of the family may be unfounded and even at odds with the wishes of the PWD.^{5,19}

There are very few exceptional circumstances in which the inclusion of the person in the disclosure process may not be necessary or advisable (i.e., in cases of severe dementia; there is a risk of aggravating symptoms in severely depressed PWD, especially when there is a risk of suicide).^{3,5,15} Even if there are concerns that PWDs may not fully understand the implications of their diagnosis, it is still recommended to include them in the process.¹⁵ Later in this article, we discuss how to minimize the negative emotional reactions to the diagnosis through education and support. There is a possibility that a small minority of PWDs may explicitly express their personal wish not to know the diagnosis. Their right not to be informed should be honoured,⁸ while the reasons for such a choice should be explored (e.g., cultural values, depression, lack of coping resources, lack of a supportive social context, etc.) for problem-solving purposes and in order to mobilize adequate support. If an informal caregiver is not already involved in the diagnostic investigations, this is a good time to ask the PWD about any family or friend who should participate in the disclosure process. Integrating a trusted family member or close friend in the process (especially in the formal disclosure meeting) has many advantages. This individual can be a very helpful informant, facilitator, and enabler. The presence of a trusted caregiver can be a source of emotional support for the PWD. Moreover, the participation of a friend/family member in the discussions can help clarify the information, facilitate the person's understanding of the issues, and enable joint decision making and implementation of future plans. Furthermore, knowing the diagnosis is the first step for caregivers to seek appropriate educational and support services to enhance their coping with their current and future caregiving responsibilities.

Although most PWDs appreciate the involvement and support of one or more of their close family members in the process, a minority object to the disclosure of their diagnosis to any third party.¹⁹ In these exceptional circumstances, the right to self-determination and privacy should be respected, unless it is clear that a person is not capable of making such a decision and there are reasons to believe that the decision is not in the person's best interests.⁸ As much as possible, attempts should be made to respect the explicit wishes and rights of the PWD throughout the process. Generally, PWDs/caregivers express a preference to have a joint disclosure meeting, while welcoming the opportunity for a private session with the physician to speak more freely about their personal needs and concerns.¹⁹

Diagnostic Disclosure and Follow-Up

The goal of disclosure meeting(s) is to formally share with a PWD/caregivers the best information available about the probable diagnosis, the likely prognosis, treatment options, future planning, and support services.¹ Often it is not possible for the PCP to adequately cover

Table 4. Diagnostic Disclosure: Meeting Emotional Needs

Explore Emotional Reactions

Anticipate a wide range of types and intensities of emotional responses to diagnosis

Be alert that PWD may have difficulty processing information and expressing emotions right away; give the person time to react and to articulate feelings

Explore emotions by paying attention to subtle cues and reflecting back perceived reactions: “I imagine this is difficult news? You seem to be quite shocked by the news.”; silence is a common reaction of shock of hearing the diagnosis

Be aware that some PWDs may have a delayed reaction or a gradual process of realization that should be addressed at follow-up sessions

Respond to Emotions in an Empathic Manner

Respect expressed emotions; let PWD know you have heard him or her and try to respond appropriately: such as words of compassion, encouragement, hope, an honest answer, more information, etc.

Acknowledge issues of loss and grief, and reassure that it takes time to come to terms with diagnosis

Explore underlying anxieties and concerns: “What are your fears about what might happen as a result of the diagnosis? Have you ever known someone with a similar condition? What was that like?”

Provide a balanced view; dispel any myths, misconceptions and stigmas (see below)

If PWD/caregiver has difficulty accepting diagnosis and questions its accuracy, respect the right to seek a second opinion, as appropriate; make it clear that referral to another physician does not mean you are abandoning the patient

Refer PWD/caregiver to a local Alzheimer Society for education, counselling and support; for a PWD who may have more extreme reactions to diagnosis, consider a referral to geriatric psychiatry services for more specialized interventions

Foster a Sense of Hope and Meaning

Be positive, but avoid the temptation to minimize seriousness of diagnosis

Explain that there are individual variations in disease progression; so, not to assume the worst

Point out that many aspects of “self” and brain functions are preserved till late stages of dementia; recognize PWD’s preserved competencies and capabilities

While encouraging proactive response to diagnosis and timely future planning, reassure that decline is rarely rapid and there is time to adapt to the illness

Focus on “living with dementia” and how to maximize positive life experiences (e.g., creating opportunities for the PWD to use his or her remaining capabilities and to remain engaged with people, places, and activities that are meaningful)

Explain that many problems associated with dementia have a solution, and there are treatment/management options that can delay deterioration and improve the quality of life for PWD/caregivers

Give encouragement that progress is being made in research all the time; so, hope for the best, while taking action to prepare for the worst

Emphasize that they are not alone in this journey; reaffirm your own commitment to PWD’s ongoing care; remind them of help they will receive from support services (e.g., Alzheimer Society’s educational programs and support groups)

Pay attention to caregiver’s emotional, educational, and support needs; ask about and monitor caregiver stress

PWD = person with dementia.

all of the information (and for the PWD/caregivers to process it) in one meeting. Thus, follow-up sessions should be arranged. A comprehensive management of the PWD’s/caregivers’ needs typically requires regular follow-up visits in order to conduct medical reassessments, manage comorbid conditions, monitor the evolution of the disease, and evaluate the response to any prescribed treatments. These visits also provide opportunities to address the PWD’s/caregivers’ psycho-social needs and

Key Points

- *Dementia diagnostic disclosure is a key medical intervention for person-centred care and optimal management of dementia.*
- *The diagnostic disclosure should not be considered a one-time event but, rather, an evolving and dynamic process, involving pre-disclosure evaluation and preparation; timely, individualized, honest, and sensitive disclosure; and post-disclosure follow-up educational and supportive interventions.*
- *This proactive, progressive, flexible, and comprehensive approach helps physicians better prepare for and manage this critical encounter, in order to optimize their patients’ and caregivers’ responses.*
- *It is important to think about the diagnostic disclosure as the first step in the process of adjustment to dementia illness (both for the persons with dementia and their caregivers).*

overall adjustment.

There are two intertwined key needs of PWDs/caregivers that should be addressed during the disclosure meeting: their information/educational needs and their emotional/support needs. An honest, open, balanced, and informative discussion of the issues in a sensitive, individualized, respectful, and empathic manner is the best approach to address both types of needs. A sensitive disclosure of a diagnosis of dementia requires physicians’ engagement on deeper levels, respect for meanings and feelings, a genuine commitment to preserve the patient’s integrity, and a deliberate attempt to instil a realistic sense of hope.^{6,8,20} As stated by a PWD, it involves “listening with the ears of your heart.”²¹ Tables 3 and 4 provide some practical tips on how to meet the information and emotional needs of PWDs/caregivers.

Generally speaking, if adequate planning has been made for the eventual disclosure meeting, all the parties involved should be better prepared for this critical encounter. This should effectively minimize any unexpected reactions and help moderate the responses to the diagnosis. Nevertheless, it is important to anticipate, and be prepared to deal with, a range of insights, emotional responses, and coping reactions. These could vary from an expression of a sense of relief and validation (from finally having an explanation for the symptoms) to a range of grief reactions of shock, anger, sadness, denial, blame, disbelief, guilt, and even, in very rare cases, suicidal ideation.^{11,14,19,20,22,23} The psycho-social needs of PWDs/caregivers should be addressed with adequate educational and emotional support, in partnership with community organizations, such as local Alzheimer societies (see Table 4). In settings when PCPs have on-site access to allied health care professionals such as social workers and nurses, these team members can make a very valuable contribution to person-centred dementia care, providing additional education and support to PWDs/caregivers throughout the disclosure process, and sharing some of the responsibilities with the PCPs.

Conclusion

Dementia is one of the most feared diagnoses by older adults, and the diagnostic process is one of the most fundamental elements in the experience of dementia.^{11,14,20,22,24} As such, the diagnostic disclosure process has been recognized as a key medical intervention for person-centred and optimal management of dementia.^{1,11,14,18,22} There have been repeated calls for more systematic research to better understand the expectations and experiences of all parties involved (PWDs/caregivers and PCPs) vis-à-vis various aspects of the disclosure process and outcomes.^{7,11,14,15,17,20} In the meantime, we hope that the recommendations made in this article provide useful guidance to PCPs to adequately prepare for and manage the diagnostic disclosure in order to optimize their patients' and caregivers' responses. To learn more regarding dementia care in the primary care setting, please refer to Aminzadeh et al.,²⁵ available at <http://www.rgpeo.com/en/health-care-practitioners/research.aspx>.

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