

PERSPECTIVE

Applying recommendations for diagnostic disclosure of mild cognitive impairment and dementia: Practical guidance for clinicians

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Abstract

A comprehensive evaluation for cognitive impairment should culminate with the communication of the diagnosis to patients and their care partners. This diagnostic disclosure sets the stage for subsequent care. Diagnostic disclosure for individuals with cognitive impairment due to Alzheimer's disease (AD) or AD-related dementias (ADRD) is particularly nuanced and requires a conscientious approach. Clinicians must assess patients' understanding and appreciation of symptoms, goals for the evaluation, and desire for information. Because AD/ADRD can impact patients' perceptions of their symptoms, it is recommended to include an informant or care partner for this assessment and for future care. Here, we provide guidance for addressing the complexities of AD/ADRD diagnostic disclosure to build clinicians' confidence in communicating diagnostic findings and a plan of care.

KEYWORDS

Alzheimer's disease and related dementias, dementia, diagnostic disclosure, mild cognitive impairment

Highlights

- Diagnostic disclosure is a key part of the evaluation of cognitive impairment.
- The disclosure process begins at the moment a cognitive evaluation is initiated.
- Care partners must be included in the cognitive evaluation and diagnostic disclosure.
- Clinicians should use patient-centered communication for evaluation and disclosure.

1 | INTRODUCTION

Timely detection of cognitive impairment and diagnosis of Alzheimer's disease (AD) and AD-related dementias (ADRD) is crucial. Once a diagnosis is determined, clinicians can provide care that improves

patient well-being, decreases care partner burden, and reduces health care costs and utilization.¹⁻⁴ Unfortunately, many individuals are unaware they have been diagnosed with cognitive impairment caused by AD/ADRD.^{5,6} As a result, they cannot access comprehensive medical and psychosocial care.

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Several factors are responsible for this problem; thus, it will take a multipronged approach to address this complex issue. Some clinicians opt not to share the diagnosis because they mistakenly believe there is little benefit to doing so.⁷ Comprehensive dementia care management programs have been found to improve quality of life.^{8–11} Moreover, the treatment landscape is changing: the U.S. Food and Drug Administration has approved anti-amyloid therapies, with more in the pipeline, that may slow disease progression.^{10,11} A diagnosis is necessary to access those treatments and resources. Another reason clinicians choose not to disclose a diagnosis is stigma or negative beliefs about people with cognitive impairment caused by AD/ADRD. Clinicians worry patients will suffer anxiety or a loss of self-efficacy if they learn their diagnosis.^{7,12} There is, however, ample evidence that most individuals would want to know if they had cognitive impairment and that those who receive such a diagnosis do not experience significant mood disturbance after disclosure.^{13–15} Addressing clinician misperceptions and attitudes regarding AD/ADRD diagnosis through educational efforts will be vital to increasing diagnostic disclosure.

Another vexing factor is many clinicians, especially primary care clinicians, report that they lack confidence in their ability to disclose a diagnosis of cognitive impairment or AD/ADRD.^{12,16} Admittedly, disclosure is often uncomfortable for the clinician; yet, if clinicians withhold a diagnosis, they also withhold the opportunity for the patient and their care partner(s) to incorporate the illness into their lives. In many cases, symptoms of cognitive impairment have already begun to affect a patient's independence, and the patient and care partner need guidance to anticipate and address challenges – for instance, medication compliance, driving, and financial decision-making – before they become urgent problems. The goal of this paper is to provide a structure and process that clinicians can use to build confidence in completing this important clinical task.

The Alzheimer's Association Clinical Practice Guidelines for the Diagnostic Evaluation, Testing, Counseling and Disclosure of Suspected Alzheimer's Disease and Related Disorders (DETeCD-ADRD CPG), published in this special issue, provide recommendations for AD/ADRD diagnosis in primary and specialty care.¹⁷ The DETeCD-ADRD CPG offer comprehensive, evidence-based guidance for performing a cognitive evaluation. Expert panels have also put forth recommendations for the disclosure of mild cognitive impairment and dementia.^{18,19} Here, we use these guidelines and recommendations to develop a structure and process for diagnostic disclosure. The recommendations herein are the product of the process used to develop the DETeCD-ADRD CPG. This process was in accordance with the best practices in guideline development described in the Institute of Medicine's *Clinical Practice Guidelines We Can Trust*.²⁰ Details of these methods can be found in the DETeCD-ADRD CPG Executive Summary of Recommendations for Primary Care Supporting Information.

We assume the clinician, having completed the cognitive evaluation, now wants to communicate the evaluation's results to the patient and care partner. Receiving a diagnosis of cognitive impairment – encompassing mild cognitive impairment and dementia – or AD/ADRD is a defining moment in a person's life. The individuals involved, disclosure setting, information conveyed, and approach to communication

all impact how individuals react to and perceive the diagnosis. Additionally, the presence of cognitive impairment may negatively affect patients' ability to engage with their diagnosis. The recommendations and resources outlined here will help primary care and specialist clinicians apply best practices for diagnostic disclosure and navigate these complexities in dialogue with patients and their care partners in their clinical encounters.

2 | CREATING A TRIAD: PATIENT, CARE PARTNER, AND CLINICIAN

Disclosure involves patients, their care partners, and clinicians. This kind of triadic relationship is unusual in the practice of adult medicine, where there is typically a dichotomy. Adults with decisional capacity are empowered decision-makers, and adults lacking capacity need a surrogate decision-maker. This dichotomy does not capture the reality of AD/ADRD care. Diagnosis and care of individuals with cognitive impairment and AD/ADRD depend on a reliable care partner. Other consensus recommendations and guidelines emphasize the critical importance of establishing a triadic relationship that involves a patient-centered communication approach, including a care partner,^{21,22} optimally from the beginning of a structured and iterative process.^{23–27}

At least three reasons support the need for a triadic relationship. First, patients may to some degree lack awareness of the nature and severity of their impairments in cognition, behavior, and function (anosognosia).²⁸ An interview with an informant can address this by providing collateral information. While it takes time and skill to interview, analyze, and integrate the information imparted by patient and informants during the diagnostic evaluation process, it is crucial to an accurate diagnosis.

Second, care partners typically have a close and longstanding relationship with patients. Their involvement creates an opportunity for supported decision-making. Many, though not all, individuals with mild cognitive impairment have marginal capacity and will benefit from having a trusted individual present to support their decisional abilities.^{29,30} Supported decision-making occurs when individuals with marginal capacity enter into an agreement with a trusted individual, such as a care partner, who assists them with making choices and decisions about their life.²⁹ Patients are more likely to trust a family member or friend with whom they have a long-term relationship in the role of a supporter.³¹ Engaging a trusted other early in the evaluation process can be a valuable accommodation for patients with cognitive impairment, allowing them to make their own decisions longer, thereby promoting autonomy. As cognitive impairment progresses, this relationship may, in time, transform from that of a supporter to that of surrogate who makes decisions about care. Early engagement promotes understanding of patients' clinical situation as well as their relevant values and interests. Involvement of a care partner is therefore crucial for clinical decision-making.

Third, engaging a care partner can assure the delivery of care. Care partners assist with activities of daily living. Initially, these are instrumental activities such as managing medications and transportation.

As cognitive impairment progresses, care partners take on activities of personal care, such as assisting with bathing and toileting. Beyond facilitating support for these activities, the involvement of a close and trusted care partner can also improve patient well-being and impact the progression and severity of their symptoms.³²⁻³⁵

Creating this triadic relationship presents challenges, particularly in the primary care setting where resources of time and space are limited. Further, individuals with subtle symptoms and minimal impairments in instrumental activities may recoil at "involving others." A patient who has decision-making capacity decides whether to include this third individual, but we feel it is advisable for the three aforementioned reasons. Patient preferences and clinical judgment can inform "when" to create a triad, but "whether" to create a triad is not in question.

Some patients will be unable to identify a trusted care partner within their family or close social networks or will have a care partner with whom their relationship is strained. Depending on the severity of the patient's cognitive impairment, we recommend engagement of a social worker, outreach to the Alzheimer's Association Helpline, or contact with an area agency on aging to obtain care management and psychosocial support as needed. Through these resources, patients without care partners can access support from social services and community organizations and may develop relationships with individuals who can assist with decision-making. For patients with a difficult relationship with their care partner, the care partner might access supports to assist with caregiver distress or identify a neutral third party that can assist with decision-making and care.

3 | SETTING GOALS FOR THE EVALUATION TO PAVE THE WAY FOR DISCLOSURE

The disclosure process starts well before the results of the evaluation of cognitive impairment are in hand. Why? By setting goals for evaluation, a clinician also sets the stage for disclosure. Pre-evaluation conversations give the clinician valuable insights into how, for example, the patient and care partner understand what is happening to the patient's cognition and function, what (if anything) they attribute any changes to, or what they hope to gain. The conversations also allow for patient and care partner education.

The clinician should use a patient- and care-partner-centered approach to the evaluation and disclosure.²² This approach has three goals: (1) to understand patient and care partner perspectives on patient cognitive symptoms, (2) to appreciate the impact of their social and cultural backgrounds on their perspectives, and (3) to establish shared goals for the evaluation process and treatment. This approach will support the partnership between the clinician and the patient-care partner dyad.

Clinicians caring for people with cognitive impairment usually face unique challenges arising from impairments in patient capacity. As a first step toward addressing these challenges, a clinician should employ an iterative process to assess the patient's understanding and appreciation of their symptoms. The patient's understanding of their illness encompasses their knowledge of the illness. Understanding depends

on both the clinician's ability to communicate information to the patient and the patient's ability to take in that information. Appreciation describes a patient's recognition that the knowledge of the illness applies to herself or himself; this is an element of identity, which is a component of autonomy.

The process of assessing understanding and appreciation might begin during the evaluation stage by asking the patient: "What is the reason for your visit with me today?" For patients who are unsure of the reason, a follow-up question could gently assess the patients' awareness of their symptoms. For example, a clinician could say, "I often see patients who have changes with their memory, which is something many people experience as they get older. Have you noticed any changes in your memory or thinking recently?" This normalizes the discussion of cognition and invites patients to share their perception of their cognition. Clinicians should attend to whether there are differences between patient and care partner understanding and appreciation.

The clinician should then probe further, assessing patient and care partner understanding and appreciation of the presence and severity of cognitive impairment and its possible etiologies. Patients could be asked to describe a typical day in their life. The clinician would then ask a follow-up question such as: "Have you ever had difficulty going about those activities you described because of cognitive changes?" Comparing the patient and care partner's responses to this question will provide insight into differences between patient and care partner perceptions. Clinicians should also assess knowledge of and concern about likely etiologies of symptoms. For example, if patients or their care partner is concerned about a cognitive change, the clinician might say, "It sounds like you have noticed a definite change in your memory and thinking. What do you think might be causing this? Is there a particular condition you are worried about?"

Discussions around any referral (eg, for neuropsychological evaluation) or testing (eg, neuroimaging) provide additional opportunities to assess patient understanding and appreciation. A clinician can explore the patient's or care partner's desire for information about the cause of the cognitive problems. A clinician might approach this by saying, "Today you told me that you are having trouble with your short-term memory. Based on your exam, I agree, there are changes in your memory that are beyond what we would expect for your age. I typically recommend a magnetic resonance imaging scan of the brain to look for causes of memory change. Is this something you would like to do?"

In the ideal circumstance, an affirmative response from both patient and care partner further supports a process that will end with diagnostic disclosure. By reiterating to the patient and care partner the reasons a test is being ordered – using the patient's or care partner's own words from the discussion of the chief complaint or reasons for the evaluation – the clinician fosters a collective understanding of the problem and describes the steps being taken to address it.

Throughout this process, support should be offered as the clinician evaluates the patient's and care partner's informational needs, assesses the potential psychosocial impact of disclosure on the patient and care partner, and identifies imminent safety and care planning needs. All communication should be tailored to individual patients and

their care partner(s) using a culturally conscious approach. If English is not the patient's or care partner's first language, the clinician should make use of a professional interpreter to mitigate a possible language barrier. Further, clinicians should consider the possibility that social and cultural factors may influence the patient's and care partner's understanding and appreciation of the illness. Clinicians should attempt to understand the patient's and care partner's cultural identity and values; attitudes toward aging, dementia, and caregiving; educational and occupational history; and literacy. Finally, all recommendations made should be culturally relevant when possible.^{36,37}

4 | WHETHER AND HOW MUCH INFORMATION TO DISCLOSE

Diagnosis of cognitive impairment or AD/ADRD allows patients and their care partners to access care that allows them to live optimally with their disease.³⁸ Therefore, once a patient and care partner agree to and complete an evaluation, disclosure should be the default. We acknowledge, however, that some circumstances may warrant limiting the information shared or withholding a diagnosis from the patient; in these cases, it would be appropriate to share this information with the care partner alone.

One such circumstance is a safety risk. Diagnostic disclosure to patients with severe, uncontrolled mood symptoms or suicidal ideation could harm mental health. While there are case reports of rare catastrophic reactions, the preponderance of evidence supports the idea that patients do not experience clinically significant mood disorders after appropriate disclosure of a diagnosis.¹⁵ An assessment of mood-related symptoms – which should be part of a routine work-up – will help reveal whether the patient is experiencing a clinically significant mood disorder. The presence of a mood disorder is not an absolute contraindication to diagnostic disclosure, but a patient who endorses or exhibits substantial anxiety, agitation, depression, or distress in relation to memory or cognitive impairment needs close assessment to determine whether, how, and when to disclose a diagnosis of cognitive impairment or AD/ADRD. If they are concerned, clinicians should ask patients' care partners how the patients might react if they were given a diagnosis of dementia or AD/ADRD. Often, mood disturbance is a symptom of AD/ADRD or can be exacerbated by the experience of cognitive decline. Thus, treatment or referral for treatment should be addressed in the patient's care plan. Once mood symptoms are better controlled, discussion of diagnostic information with the patient can be revisited.

Another circumstance in which clinicians might disclose a diagnosis to care partners only is when patients lack insight into the nature or severity of their cognitive or behavioral impairments.²⁸ This could impact patients' perception and acceptance of disclosed information and may also lead to significant distress or conflict with care partners if certain topics are discussed.

Finally, family members may request that the specific diagnosis be shared with them and not with patient due to a patient's desire not to know certain information or because of differences in cul-

tural norms.^{39–42} These requests should prompt a conversation with patients and their family members, using approaches discussed in Section 6, to determine their reasons for withholding a diagnosis. In particular, patients' desire to know information should be assessed. Prior to initiating any diagnostic testing, the clinician might ask the patient, "If you had a condition, such as Alzheimer's disease, that caused progressive memory loss, would you want to know that?" If the patient indicates she does not want to know, it is important to ask why. Misconceptions about AD/ADRD or stigma can often lead to a desire not to know. After discussing these issues, if the patient still wishes not to know, she should be asked who she would like to involve in discussions of her health and health care. If the patient wants to know the diagnosis, but family members do not want this information shared with the patient, the clinician should try to understand and, if possible, alleviate family members' concerns about disclosure. Ultimately, the clinician should discuss the diagnosis with the patient if the patient has expressed a desire to know. It may be helpful to engage a social worker in these discussions to sort out care partners' concerns.

Addressing these circumstances provides data that will guide elements of the evaluation and help clinicians and care partners weigh the risks and benefits of disclosing the diagnosis to the patient. Table 1 provides additional example questions for clinicians to pose to patients and care partners to assess these issues.

Clinicians must also recognize how the 21st Century Cures Act⁴³ provisions intended to speed patients' access to their electronic health information, including diagnostic test results and clinical notes, impact diagnostic disclosure. As a result of this act, patients can access test results immediately – before the results can be integrated into a disclosure discussion. If patients have granted their care partners access to their electronic health information, the care partners will also be able to see the results. While information sharing promotes patient autonomy, clinicians must take care to ensure that patients and their care partners have context for any information they might see. It may also be beneficial to ask them to consider whether they want to review this information before the clinician is able to discuss it with them or to wait and review it with the clinician.⁴⁴

5 | DISCLOSURE SETTING

The disclosure process typically occurs over the course of multiple clinical encounters as more information is gathered over time. For example, the fact of cognitive impairment will likely be addressed at one visit while the cause of that impairment will be addressed at a later visit. Disclosure conversations may take place during an in-person clinical visit or remotely via telehealth. These settings can support communication between the patient, care partner, and clinician.

Clinicians are encouraged to conduct disclosure discussions in a private, distraction-free space. This may be easier to achieve in a clinic where there are private exam rooms as opposed to in a telemedicine visit, though in-person meetings may need to be moved to a larger office or conference room if multiple care partners are present. In the case of telehealth, the clinician should instruct patients and care

TABLE 1 Prompts to evaluate risks and benefits of AD/ADRD disclosure.

Topic	Questions for patients and/or care partners
Understand goals for evaluation	<p><i>Patient and care partner:</i></p> <ul style="list-style-type: none"> • What is the problem that brings you here? • What are your goals for our visit? • What information would you like to know? • If [patient name] had Alzheimer's disease, would [patient name] want to know?
Assess patient's awareness of cognitive and/or behavioral symptoms	<p><i>Patient:</i></p> <ul style="list-style-type: none"> • Are you having any difficulties (or changes) with your memory or thinking? • Is your memory or thinking any different than it was 5 or 10 years ago? • Do others around you tell you they have noticed changes in your memory or thinking? Do you agree or disagree with them? <p><i>Care partner:</i></p> <ul style="list-style-type: none"> • Does she/he seem aware that she/he has had a change in memory or thinking? • Does she/he behave appropriately in social situations?
Evaluate for significant mood disturbance	<p><i>Patient:</i></p> <ul style="list-style-type: none"> • How would you describe your mood over the last few months? • Have you had thoughts of harming yourself or others within the last few months? If so, have you ever acted on those thoughts? <p><i>Care partner:</i></p> <ul style="list-style-type: none"> • Has she/he been physically aggressive toward others in the last few months? • If she/he were diagnosed with [AD/ADRD], how might she/he react to that news? • Do you worry about her/his safety or your safety if she/he were to receive a diagnosis of AD/ADRD?

partners to move to a space where they feel comfortable speaking freely and will not be disturbed. This is to ensure that sensitive information can be shared openly and that patients and care partners can devote their full attention to the discussion.

The practical considerations for achieving the most effective triadic communication are often complex and can, in some circumstances – and particularly in primary care settings – be challenging to accommodate.^{12,16,38,45} For example, the most honest history from an informant may be best obtained away from the patient. Yet some clinicians' offices may not be physically or operationally designed to optimally accommodate a patient and care partner. Relationship dynamics between patients and their family members or informants/care partners can be complicated and may necessitate several streams of communication and separate spaces.

6 | DIAGNOSTIC DISCLOSURE CONTENT

The purpose of diagnostic disclosure is to explain a patient's illness accurately and compassionately to the patient and care partner. Patient and care partner informational needs, patients' capacities, and clinicians' judgments about the likely impact of diagnostic information on patients and their care partners will guide the content and approach of information sharing. As discussed in Section 4, patients may come to visits already having accessed some information through their electronic medical records. It helps to ask whether they looked at the results and, if so, to explain what they learned.

The first element of the diagnosis disclosed should be syndromic diagnosis of mild cognitive impairment or dementia, as this is based on

the initial history, focused examination, and cognitive and functional assessments. Education around the meaning of these terms should be provided – that is, they describe the severity of cognitive impairment a patient is experiencing. A clinician might state, "Last time we talked, you told me you were experiencing short-term memory loss, but it is not preventing you from carrying out any of your daily activities. Your cognitive testing supports what you told me. It shows you do have troubles remembering new information. Based on this, I would describe your symptoms using the term 'mild cognitive impairment.'" The patient should be informed that the terms mild cognitive impairment and dementia do not describe the cause of their symptoms or etiologic diagnosis. Disclosure of that comes next.

Possible causes of the syndromic diagnosis should be discussed so that patients and care partners are reminded of the rationale for diagnostic testing. For example, "There are many different causes of mild cognitive impairment, some of which are conditions that cause changes to the structure of the brain, leading to changes in memory or thinking. These conditions could include strokes or diseases like AD, which causes progressive memory decline over time. You completed a brain MRI to look for evidence of those brain changes." This will then lead to a discussion of the pertinent findings and, ultimately, disclosure of etiologic diagnosis. With the emergence of testing to detect markers of AD, such as blood-based biomarkers, clinicians must be able to discuss the meaning of these results with patients. The approach to AD biomarker testing and disclosure proposed by Largent and colleagues is a helpful guide for clinicians to gain this proficiency.⁴⁶

Several approaches have been developed to help clinicians structure the delivery of information about a diagnosis of cognitive impairment due to AD/ADRD.^{25,47,48} These methods provide a psychologically

TABLE 2 SPIKES protocol for AD/ADRD diagnostic disclosure.

Step	Goals	Example language
S: Set up interview	<ul style="list-style-type: none"> Physically set up a private, quiet space Verbally set up the context and goals for the visit 	<p>"Today I would like to review the results of the testing we have gathered since your last visit. Is that okay?"</p> <p>"Before we get started, is there anything else you want to make sure we discuss during today's visit?"</p>
P: Assess the patient's (and/or care partner's) Perception	<ul style="list-style-type: none"> Understand the patient's (and/or care partner's) understanding and appreciation of their symptoms Determine if their perception of their symptoms has changed since the beginning of the evaluation process Assess their knowledge of causes of cognitive decline 	<p>"Last time we met, you told me that you've had some trouble with your memory, and that your spouse notices it more than you do, but it doesn't bother you most of the time. Is that still the case?"</p> <p>"Have you thought about what might be causing your memory changes? If so, what do you think might be the cause?"</p>
I: Obtain the patient's (and/or care partner's) Invitation	<ul style="list-style-type: none"> Assess whether the patient (and/or care partner) would like to know the cause of their symptoms Understand what types of information they do or do not want to learn (eg, diagnosis, stage, prognosis) Assess the patient's emotional readiness to receive the information 	<p>"Would you like to know the cause of the symptoms you and your spouse have noticed?"</p> <p>"Supposed you had a disease that was causing your memory and thinking problems. Would you want to know that? What else would you want to know about it?"</p> <p>"Does having this conversation bother you? If so, would you like to proceed?" <i>[If not, probe further to understand why and attempt to address concerns; if patient is visibly agitated, consider limited disclosure of facts to patient]</i></p>
K: Give Knowledge and information	<ul style="list-style-type: none"> Provide results of testing with empathy Disclose syndromic diagnosis, etiologic diagnosis, and stage May also discuss prognosis if desired by patient and care partner Invite questions from patient and care partner 	<p>"I'm sorry that I don't have better news to share with you."</p> <p>"I know I've said a lot here. Before we talk about next steps, let me pause and see what questions either of you have."</p>
E: Address Emotions with empathy	<ul style="list-style-type: none"> Acknowledge the emotional impact of the diagnosis Provide opportunity for the patient and care partner to express their emotions Offer support 	<p>"This is a difficult diagnosis to receive. I'm sorry you're going through this."</p> <p>"How are you feeling about what we've discussed?"</p> <p>"You are the same person now as you were before you came to see me. I've given you a diagnosis to explain the symptoms you have been experiencing. Now we will work together to help you live well with that diagnosis."</p>
S: Strategy and Summary	<ul style="list-style-type: none"> Provide a preview of a management plan aligned with the patient and care partner's goals and needs Discuss follow-up plan Reassess understanding Provide a verbal and written summary of the most relevant information 	<p>"Is there anything you would like me to discuss further? Do you have any other questions?"</p> <p>"I would like to see you again in a few months to check on how you're doing and address any concerns that may come up. You can always reach out to me before then if you would like."</p>

supportive framework for the clinician to convey diagnostic information about a serious illness in the context of a patient's perceptions, values, informational needs, and goals. There are other well-known approaches to delivering difficult news, developed in the oncology and palliative care community, which can be applied without modification to AD/ADRD diagnostic disclosure. One commonly used approach is the six-step SPIKES protocol for breaking bad news. The steps of the SPIKES protocol are as follows: (1) Set up interview, (2) assess patient's Perception, (3) obtain patient's Invitation, (4) give Knowledge and information, (5) address Emotions with empathic responses, and (6) present Strategy and Summary.⁴⁹ Table 2 details the goals of these steps and provides additional examples of language to accomplish each step for AD/ADRD diagnostic disclosure. Patients and their care part-

ners should be expected to have an emotional response to receiving this news. As part of step 5 of the SPIKES protocol, "address Emotions," patients and care partners should be given the space and opportunity to experience and name these emotions. Those who experience significant emotional distress may benefit from counseling to help process their emotions and learn coping and emotional regulation techniques.

Another comprehensive approach to the communication of bad news is the Serious Illness Care Program, which aims to improve conversations about values and goals for patients with serious illnesses.⁵⁰ The motivation for this program was based on evidence that early goals-of-care discussions are associated with better quality of life, reduced utilization of non-beneficial medical care, enhanced goal-consistent care, positive family outcomes, and reduced costs.⁵¹ This

program aims to train and support clinicians in integrating best practices in advanced care planning in the care of their patients, to optimize the alignment between patient goals and the medical care they receive, and to enhance the quality of life throughout the illness. Although developed for discussing information about poor prognosis in patients with established diagnoses of cancer,^{52,53} the program is being applied to patients with a variety of other life-threatening illnesses,^{54,55} and the principles are very relevant to the care of patients with cognitive impairment.

One of the practical elements of this program is the Serious Illness Conversation Guide, which provides a psychologically supportive structure for these conversations similar to the SPIKES protocol. A benefit of the Serious Illness Conversation Guide is that it contains patient-tested language. It emphasizes the importance of a clinician-guided dialogue in which patients are asked about their understanding of their illness, decision-making and information preferences, goals and fears, views on acceptable function and trade-offs, and preferences for family involvement, allowing the clinician to disclose medical information about the serious illness in this personalized context.

Once an etiologic diagnosis has been made, disclosure of this information will guide a discussion of stage and prognosis; treatment options and expectations, including treatment efficacy (eg, symptomatic improvement vs slowing of clinical decline), side effects, and benefit-risk calculus; patient safety concerns, such as home safety, driving, and financial and legal decision-making capacity; and resources for education, care planning and coordination, and support services.

7 | CONCLUSION

Without a diagnosis, people struggle to make sense of their symptoms, and care is hard to deliver. Advances in the ability to measure cognition and detect the pathologic markers of the diseases that cause cognitive impairment provide clinicians with a means to make a diagnosis. Advances in drug treatment and the value of care partner services and supports amplify the importance of diagnosis and the neglect from the failure to do it. But dementia and the diseases that cause it are fraught with dread and foreboding. Clinicians therefore need a structured approach to deliver the diagnostic information to patients and their care partners. Practical guidance for disclosure empowers clinicians to communicate a diagnosis clearly and confidently and sets the stage for devising a comprehensive care plan that is individualized to meet the unique needs of patients and their care partners.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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