

# Helping Patients With Dementia and Caregivers Live Well

We can find art in Alzheimer's disease.

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*Life does not stop with a diagnosis of dementia: with the right support, living well is not tokenism, it is possible.*

– Jules Morgan<sup>1</sup>



## Barriers to Helping Patients Live Well

There is a recent surge of new diagnostic modalities and therapeutic options for many neurologic conditions. As a



result and combined with the time constraints and regulatory requirements that neurologists (and all health care professionals) face, this can create situations in which detailed disease management, rather than the healing potential within the provider-patient relationship, directs clinical encounters. For conditions without effective treatment or cure, placing clinical interactions firmly within such a therapeutic relationship may be especially important.

Alzheimer's disease (AD) and related dementias can be particularly treacherous ground for neurologists. In addition to having no cures or consistently effective treatments to offer, neurologists also may lack the training or experience to field questions posed by caregivers, often on the theme of managing challenging behaviors. Likewise, neurologists may not fully understand the plight of the caregiver and so may be unable to offer informed advice that could ease the burden of caregiving, which in turn can improve the quality of life for persons living with dementia. First-person accounts that could educate neurologists on what it is like to live with dementia call to mind unconscious biases neurologists may harbor regarding patients with dementia, suggesting that targets for care and support are scarce in the medical literature on AD.

The Alzheimer's Association reports that only 45% of people with AD are given a diagnosis by their doctor.<sup>2</sup> It may be difficult for physicians to tell patients they have a disease that cannot be stopped or slowed, fearing the stigma-fueled emotional reaction an AD diagnosis can cause.<sup>3</sup> In fact, doctors are much more likely to level with patients who have cancer than patients who have AD.<sup>3</sup>

In a 2014 *New York Times* essay, Danielle Ofri, MD posited possible causes for this phenomenon, including physicians' frustration at the lack of effective treatments and time constraints and the existential and emotional aspects of themselves they may not be aware of or may tend to avoid.<sup>4</sup> Burnout affects up to 60% of neurologists and produces impairments in judgment, poorer patient outcomes, and increased likelihood of patient objectification.<sup>5</sup> Burnout also may affect the ability to follow through in breaking of bad news and may inhibit the expression of empathy and compassion in clinical encounters.

Numerous persons living with dementia have communicated with the authors of this article about the negative impact their interactions with neurologists have had on them, especially when receiving the diagnosis of dementia. In 2 recent national conferences (Dementia Action Alliance in 2017 and American Academy of Neurology in 2018), there have been panel discussions of persons living with early-onset dementia from various causes. The interactions these individuals describe often are characterized as lacking empathy, compassion, or acknowledgement of fundamental personhood with poor eye contact and communication skills of the neurologist, ignorance or poor communication of available resources, and a perceived lack of effort or concern to help patients live well with their diagnosis. Interactions such as these may have far-reaching consequences, including undermining trust in physician-patient

relationships, negatively affecting treatment plan compliance, and affecting patients' perceived self-worth and caregivers' well-being.

First-person accounts like these can be informative, and the authors of this article advocate for using them to educate providers by including them in medical education from premedical training through medical school, residency, and continuing medical education. Research, including accounts such as these, shows that persons living with AD feel unsure of themselves in an unfamiliar world and try to restore normalcy through maintaining a sense of continuity in their lives.<sup>6</sup>

### Personhood, Relationships, and Empowerment Promote Living Well

In 2007 and 2008, the Alzheimer's Association led a series of town hall meetings designed to listen to and directly engage with people diagnosed with dementia<sup>7</sup>; 300 individuals living with dementia were interviewed. Rather than responding about the personal or functional impact of dementia, participants focused on poor interactions with physicians during and after diagnosis, as well as how the stigma of dementia changed the way they were treated by others after diagnosis.<sup>8</sup> Participants perceived the social reaction of the medical community, loved ones, and society in general as more damaging to their well-being than the disease itself, highlighting the social impact of dementia beyond its effects on physical and cognitive function. The stigma of being diagnosed and the immediate implications for control and autonomy in everyday decisions were of primary concern to town hall participants.<sup>8</sup>

Reed and colleagues<sup>9</sup> posit what they term a *tragedy discourse*, a negative lens through which dementia is typically considered, as the dominant frame for understanding dementia, perpetuated in media and popular culture. This paradigm emphasizes losses (eg, ability, identity) despite evidence that people living with dementia retain their selfhood,<sup>9</sup> and may continue to be productive, often discovering previously unknown talents and abilities.<sup>10</sup>

The tragedy discourse perpetuates stigma and is used as an inappropriate justification for denying persons with dementia opportunities for autonomy and engagement. In contrast, transcending this disability-focused dementia paradigm may contribute to an understanding of dementia that is more aligned with respect, dignity, and social justice. This may in turn enhance the well-being of people living with cognitive impairment by helping to maintain their sense of selfhood and relationships.<sup>8</sup>

Attention to sense of self and relationships are of primary importance when caring for people with cognitive impairments. Recognition and acceptance of a persistent sense of self among people living with dementia is the prerequisite

for person-centered care, with inherent ethical implications supporting deference to those living with dementia regarding decision making, autonomy, and self-determination.

Acknowledging that identity and selfhood occur in a reciprocally relational context, some dementia care professionals and researchers are reframing person-centered care as relationship-centered care.<sup>8</sup> The premise is that optimal care and support are achieved when all involved parties (ie, the person living with dementia and his or her family and professional care partners) experience a sense of security, continuity, belonging, purpose, achievement, and significance in the shared goal of living well with dementia.

### Neurologists Can Help Patients Live Well

The question of what constitutes living well is important to address. The authors of the IDEAL study, a cohort of people living with dementia and their caregivers across Great Britain offer the following definition: maximizing life satisfaction, reaching one's potential for well-being, and experiencing the best possible quality of life in the context of the challenges that dementia presents for individuals, relationships, and communities."<sup>11</sup>

### Delivering the Diagnosis

Neurologists are often consulted to make or confirm a diagnosis of dementia of a specific cause, and this may become increasingly true given the new diagnostic paradigm of the 2018 National Institute on Aging-Alzheimer's Association (NIA-AA) Research Framework. The NIA-AA framework distinguishes AD from Alzheimer's clinical syndrome by the presence or absence of biomarkers.<sup>12</sup> This puts neurologists in a critical position to influence the tone and trajectory of care, starting with the diagnosis.

Some persons living with dementia report negative interactions with their neurologists at the time of diagnosis. Box 1 outlines key recommendations of an expert consensus panel for sharing the diagnosis and management of AD, touting early diagnosis and the implementation of psychosocial interventions that provide support, education, and counseling to patients, all of which result in quality-of-life improvements.<sup>13</sup>

Although tailored to primary care providers, most of these guidelines are appropriate for neurologists. Of particular importance is to "counter nihilism and despair by focusing on the functional capabilities that remain and framing the challenge as one of achieving the best life possible while accommodating the limitations of the disease."<sup>13</sup> More than 1 clinical interaction may be required because of complexities and demands of sharing the diagnosis and the potential psychologic and emotional impact it may have.

It is important to explicitly name the diagnosis and provide ample educational resources and information on

## Box 1. Key Recommendations of Expert Consensus Panel for Sharing Diagnosis and Management of Alzheimer's Disease

1. Arrange for the participation of a primary caregiver during diagnosis discussion.
2. Provide adequate uninterrupted time and a proper office space.
3. Make a specific diagnosis, unless cultural, educational, or other factors dictate otherwise.
4. Make the diagnosis a process that occurs over several office visits.
5. Counter nihilism and despair by focusing on remaining abilities: frame the challenge as one of achieving the best life possible while accommodating the limitations.
6. When sharing the diagnosis, it is recommended that the physician position himself or herself as a partner of, and advocate for, the patient and caregivers.
7. Set realistic expectations for treatment.
8. Initiate early comprehensive treatment, including psychosocial interventions.
9. Educate patient, caregiver, and other family members about Alzheimer's disease in stage of disease—appropriate manner, using all available educational resources.
10. Inform the patient and caregiver(s) of available services and encourage their utilization; provide in-office materials and website addresses.
11. Emphasize to the caregiver the importance of attending to his or her own emotional and health care needs and facilitate access to resources.
12. Address commonly occurring issues proactively, especially if safety related.

support services available to counter the shame and stigma associated with insufficient knowledge.<sup>13</sup> Ancillary staff can collate these resources and make them available to patients and caregivers in a postdiagnosis meeting, as is often done effectively in oncology practices.

The Alzheimer's Association published *Principles for a Dignified Diagnosis* in 2016, the first statement of its kind written by people living with dementia about the AD diagnosis experience that provides additional recommendations (Table).<sup>15</sup>

### Caring for Patients After Diagnosis

Physicians and their office staff members should position themselves as partners and advocates for both persons living with dementia and their caregivers. Neurologists should

mention the possibility of enrolling in clinical trials and be aware of research sites enrolling subjects if desired by their patient.<sup>13</sup>

Direct communication with persons living with dementia that maintains eye contact and avoids emotional reactivity is essential. Neurologists should approach patients from the front at eye level and pose questions slowly, clearly, and singly, with ample time for unprompted responses.<sup>14</sup> Caregivers can and should be queried, as well, but not as surrogates for the person living with dementia. We recommend that even in cases of advanced disease, the physician give the same deference, respect, and attention to a person with cognitive impairments that they would give to a person without cognitive impairments. Although accurate historical data may also need to be provided by caregivers, the effort to avoid regarding persons living with dementia as anything less than complete human beings preserves their innate dignity, personhood, and unique narratives.

The Dementia Action Alliance, a nonprofit organization of people living with dementia, care partners, dementia specialists, and others has published a list of the top 7 things doctors need to know to enable, rather than disable, a person living with dementia (Box 2).<sup>16</sup>

It is important for neurologists to offer hope by emphasizing that life goes on despite dementia, and that self-expression and maintenance of relationships are essential for well-being. Supporting strengths and minimizing losses within a loving, trusting, accepting, and validating social framework creates a safe environment where persons diagnosed with dementia can be empowered to live to their potential. Neurologists should educate patients and caregivers from within this type of dementia care paradigm.

Both persons with cognitive impairment and caregivers identify quality of life as a central goal of treatment.<sup>17</sup> Many individuals with dementia rate their overall quality of life as good or excellent, despite losses that some would consider devastating.<sup>17</sup> Positive mood and engagement in pleasant activities are essential features of good quality of life. Care providers have anecdotally reported that such meaningful activity provides a sense of efficacy, reduction in depression, and improved relationships with family members.<sup>17</sup>

### Evidence-Based Interventions

There are evidence-based interventions that improve quality of life for individuals living with dementia.<sup>17</sup> These include behavioral and caregiver education interventions, occupational therapy, caregiver supervised exercise programs, cognitive-stimulation sessions (eg, memory training, problem-solving, mnemonic devices, multisensory stimulation, word games, puzzles, and social activities), and participation in support groups of people with early-stage AD.<sup>17</sup> The latter promote social interactions with a peer

TABLE. PRINCIPLES FOR A DIGNIFIED DIAGNOSIS

Patient's Need	Rationale
Talk to me, the person living with dementia, directly.	I am the person living with the disease, and though those close to me will also be affected, I am the person who needs to know first.
Tell the truth.	Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
Test early.	Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential, and access information and resources.
Take my memory concerns seriously, regardless of my age.	Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s, and 60s.
Deliver the diagnosis in plain but sensitive language.	My diagnosis may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.
Coordinate with other care providers.	I may be seeing more than one doctor. It's important that you talk to my other care providers to ensure everyone has the information so that changes can be identified early, and I won't have to undergo unnecessary repeated testing.
Explain the purpose of different tests and what you hope to learn.	Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take, and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.
Give me tools for living with this disease.	Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, what medical treatments are available, and what support and resources are offered in my community.
Work with me on a plan for living a quality life.	Medication may help modify some of my neurological symptoms, but I am also interested in recommendations for keeping myself as healthy as possible through diet, exercise, and social engagement.
Recognize that I am an individual, and the way I experience this disease is unique.	This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life.
Alzheimer's disease is a journey, not a destination.	Treatment doesn't end with the writing of a prescription.
Please continue to be an advocate.	Advocate not just for my medical care but also for my quality of life as I continue to live with Alzheimer's disease.

group, which has been identified as enabling by persons living with dementia.<sup>16</sup> Memory Cafes, first implemented in the Netherlands by psychologist Bère Miesen, are gatherings where people with cognitive impairment and their caregivers come together to make new friendships and support one another, often incorporating art, music, and other modes of creative expression. More than 200 of these cafes have begun in the United States.<sup>18</sup>

*Creative arts therapy.* A growing body of research shows that expressive arts and creativity counterbalances social stigma for people diagnosed with dementia by building a social and emotional framework for strength-based living.<sup>19</sup> Art therapy, music therapy, drama therapy, poetry and bibliotherapy, and dance therapy combined with reminiscence

and storytelling have numerous beneficial effects including fostering dignity, preserving a sense of self-worth, and improving quality of life.<sup>20</sup> Trained and credentialed therapists in these disciplines work in a defined clinical relationship with clients to support personal and relational treatment goals and promote well-being, resilience, and joy in the creative process. Neurologists should recommend these therapies and consider making referrals when feasible.

Art therapy improves attention, pleasure, behavior, and affect in patients with dementia.<sup>21</sup> Other benefits include enhanced self-esteem, improved communication and reduced anxiety, agitation, and depression.<sup>21</sup> Art therapy for patients with dementia is typically provided to small groups of patients in a clinical or care setting by a regis-

## Box 2. The Top 7 Ways to Enable a Person With Dementia

1. Provide me with the diagnosis of dementia promptly and with compassion and support.
2. I am your patient. Please talk to me and not my care partner instead.
3. Provide me with written information about the type of dementia I have and with resources to peer groups.
4. Encourage me to participate in peer groups.
5. Understand that I am LIVING WITH dementia and need your support.
6. Encourage me to continue doing things that are enjoyable and meaningful.
7. Inform me about effective compensatory strategies others use when abilities change.

tered art therapist. Therapists can be found through the American Art Therapy Association.

In the last decade, a growing number of museums have initiated art appreciation programs for persons living with dementia and their caregivers. *Meet Me at MoMA* (Museum of Modern Art, New York, NY) is the best-known of these where trained curators lead small groups of persons with dementia and their caregivers in a viewing and discussion experience of a limited number of works of art.<sup>21</sup> Some programs, such as *Cognitive Connections* (Cognitive Dynamics Foundation, Tuscaloosa, AL), also combine making art with the viewing experience.<sup>22</sup> Research studies have shown improvement in mood of both patients and caregivers during sessions, and improved self-esteem in patients lasted for days. In addition, caregivers felt a greater social connection and fewer emotional problems.<sup>21</sup>

The painting on the cover and the Figure were painted by Lester E. Potts, Jr, father of neurologist, Daniel C. Potts (see *About the Artist*, p. 7). Figure 1 depicts an original watercolor painted when he was experiencing mid-stage AD. Participating in art therapy improved his communication and behavior, elevated his mood, and helped preserve his relationships, restoring a sense of pride and self-worth. His treating physicians helped their patient live well by referring him to a dementia daycare center offering expressive arts therapies. The painting shown, *Lester and Albert*, depicts Potts with a fellow sawmill worker and friend, exemplifying the transcendent power of relationships in the face of advancing dementia.

### Promoting Brain Health

Neurologists should make many of the same recommendations for maintaining brain health to persons with dementia and their caregivers as they make to other patients (eg,



**Figure. *Lester and Albert* by Lester E. Potts. Creative arts programs can help maintain relationships for patients with dementia.**

physical exercise, a brain- and heart-healthy diet, good sleep habits and assessment and treatment for sleep apnea, treatment of mood disorders, avoidance of smoking and excessive alcohol intake, controlling vascular risk factors). Furthermore, neurologists should encourage patients and caregivers to attend to spiritual wellness through prayer, meditation, sharing in faith groups, and other spiritual practices.

### Providing Safety Guidelines

Helping patients to live well with dementia includes giving guidance on issues of safety, such as driving, firearms, falls prevention, wandering, and other environmental safety issues. The neurologist should recommend GPS devices if wandering risk is significant, and formal driving assessments by physical therapists can aid in determining whether driving restriction is indicated. If restriction is needed, physicians should take the lead, as this can be a very difficult and divisive issue for families.<sup>14</sup>

### Health Care Transitions and Legal Considerations

Neurologists should also advise family caregivers to seek legal counsel for power of attorney, health care proxy, long-term care planning, potential participation in a clinical trial, and other issues. Health care transitions can be particularly stressful (eg, home to hospital, hospital to assisted living facility or nursing home) and often precipitate challenging behaviors. Neurologists can provide valuable guidance, support, and treatment during such times. Neurologists should be willing to advise family caregivers on the appropriate time to consider advanced-care options such as adult daycare centers, specialty-care assisted living units, nursing homes, or trained professional caregivers for the home. End-of-life care, including hospice and palliative care, should be addressed at the appropriate time as well.<sup>14</sup>

## Caring for Caregivers

Helping persons with dementia to live well necessitates considering the caregiver. Neurologists have an ethical responsibility to concern themselves with caregiver health and well-being in the context of the relationship-centered care model.<sup>23</sup> Caregivers are essential partners in health care management for persons living with dementia; their knowledge, well-being, and sustained engagement with health care providers are critical to the success of both medical and psychosocial components of care. Ethnic, socioeconomic, and gender disparities are important influences on the quality of dementia care and should be considered, as well.<sup>24</sup> Caregivers could benefit from simply being asked how they are faring by a compassionate listener who also provides reassurance, support, and education.<sup>25</sup>

## Summary

Neurologists are in a unique position to promote a more compassionate culture in dementia care, from the time of diagnosis all the way through to end of life. By considering the voices of those who are living with dementia and their caregivers; seeking to honor the dignity and personhood in every human being, despite conditions or circumstances; making the commitment to educate themselves, staff, patients, and caregivers; and positioning themselves as partners and advocates in relationship-centered care models, neurologists can play an essential role in helping patients with dementia and their caregivers live as well as possible. ■

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## Disclosure

*The authors have no financial relationships to disclose.*