

# Stigma of Alzheimer's Disease Dementia

Clinicians can address the challenges of stigma in routine clinical practice.

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Neurologists often are asked to evaluate and care for individuals with mild cognitive impairment (MCI) or dementia. Receiving a diagnosis of Alzheimer's disease (AD),

the most common cause of dementia and MCI, presents patients and their families with psychological and social challenges. Many of these challenges are the consequence of stigma. The social stigma associated with the diagnosis can have wide-reaching and lasting consequences for how a patient and caregiver react to the diagnosis (internalized stigma) and how others might treat them (public stigma). It can hinder their daily lives and well-being, leading to depression, isolation, and discrimination. It can also discourage participation in research, impeding efforts to discover an effective therapy. Fortunately, neurologists and other clinicians can take steps to minimize stigma.

## What Is Alzheimer's Disease Stigma?

In medicine, stigma describes how a person's social status and sense of self may be tainted and devalued after being linked with a disease that has negative social connotations.<sup>1</sup> A disease label links the person and the discrediting characteristics.<sup>1</sup> When a clinician diagnoses a person with AD, the label implies what signs and symptoms the person may have and be expected to develop. These ideas often inform stereotypes, which are oversimplified, exaggerated, or otherwise inaccurate generalizations about individuals with the disease, and as a result, the ways people feel about themselves and how others feel about and treat them.<sup>1</sup> Three types of stigma affect persons with AD dementia.

*Public stigma* describes how members of the general public have negative or pejorative beliefs that cause them to act in discriminatory, exclusionary, or patronizing ways toward either patients or persons closely associated with the patient.<sup>2</sup> Public stigma can be overt, like discrimination, although other times it may be subtler, like a prejudicial belief that a patient is incompetent.

Persons living with a diagnosis of AD can experience *self-stigma*.<sup>2</sup> This describes a person cognitively or emotionally absorbing negative beliefs, attitudes, assumptions, and stereotypes related to the disease, such as feeling ashamed and inferior because of being associated with the disease. Self-stigma can lead to depression, avoidant coping, social withdrawal, low self-esteem, hopelessness, worsened psychiatric symptoms, and decreased help-seeking behaviors.

Caregivers and family members can also experience stigma.<sup>2</sup> *Spillover stigma* describes how people who do not have AD are affected by the stigma related to the disease. It often affects individuals who share close social proximity to those who have the disease, such as caregivers.<sup>3</sup> It can also include individuals who have a different but similar condition. In particular, the stigma ascribed to dementia can spill over into the lives of persons with MCI. As a result of spillover stigma, individuals can experience many of the same social and psychological consequences as individuals with AD dementia.

## Identifying and Addressing Stigma in Clinical Practice

Neurologists and other clinicians can help patients and their caregivers address stigma and limit or prevent its consequences. Common consequences of AD stigma include isolation and social withdrawal, interpersonal stress, depression, and threats to personal identity such as loss of dignity and the internalization of stereotypes.<sup>2</sup> We discuss 5 ways that clinicians can help limit or prevent common consequences of stigma: personalize the experience, ask specific and tailored questions, support dignity through language, help patients and caregivers access self-care, and foster engagement. The Table summarizes these approaches and the steps to address them.

### Personalize and Validate Experiences

Stereotypes comprise a key component of AD stigma.<sup>2</sup> A stereotype is a widely held, fixed, and oversimplified idea. The mass media is a common source of stereotypes about AD that

TABLE. APPROACHES TO ADDRESS THE STIGMA OF ALZHEIMER'S DISEASE DEMENTIA

APPROACHES	ACTION STEPS	EXAMPLES
<p>Personalize and validate</p>	<ul style="list-style-type: none"> <li>Challenge stereotypes through direct discussion</li> </ul>	<ul style="list-style-type: none"> <li>For both patients and caregivers: "There is no one way to 'have Alzheimer's disease.' It can differ from one person to another, and that's okay."</li> <li>For caregivers: "You're living a struggle: trying to do everything you possibly can for your relative and at the same time living your life. You can't fight this, but you can come to terms with it."</li> </ul>
<p>Ask about beliefs, worries, and experiences related to Alzheimer's disease dementia</p>	<ul style="list-style-type: none"> <li>Correct misinformation</li> <li>Adjust expectations to be more accurate</li> <li>Refer to allied health professions for psychological therapy and social support, as appropriate</li> </ul>	<ul style="list-style-type: none"> <li>"Tell me what you know about Alzheimer's disease?" [Use answers to this to correct beliefs that are false or exaggerated]</li> <li>"Many people worry that a person will no longer be able to make medical decisions for themselves because of a diagnosis of Alzheimer's disease. Is this something you worry about?"</li> <li>In caring for a patient with mild-stage dementia or MCI: "Some people fear that after just a year or so they'll not be able to live in their home or recognize family. Let me assure you that we diagnosed this quite early. Those kinds of problems are years and years away."</li> </ul>
<p>Foster dignity in language</p>	<ul style="list-style-type: none"> <li>Use person-centered terms</li> <li>Use accurate, respectful, inclusive, and empowering phrases</li> <li>Leave room for individual experience by avoiding "absolutes"</li> </ul>	<ul style="list-style-type: none"> <li>"Individual living with dementia" or "a person with dementia"</li> <li>"It's common for people living with dementia..." rather than "Alzheimer's disease causes people..."</li> <li>"You are the same person now after I have told you this diagnosis as you were before you came to see me. All that I've done is given an answer to what's causing your memory problems."</li> </ul>
<p>Help individuals access self-care</p>	<ul style="list-style-type: none"> <li>Ask what individuals do to engage self-care</li> <li>Offer resource lists of activities that can be done at home, in the local community,</li> <li>Offer lists of self-care strategies like avoiding drugs and alcohol, eating well-balanced meals, giving oneself permission to feel (good and bad), and exercising even if it's only a little bit, like a walk around the neighborhood</li> </ul>	<ul style="list-style-type: none"> <li>When talking with the caregiver: "Taking care of yourself is very important for your health. It can sometimes feel hard, like the time it takes should be used to take care of your [father/mother/sibling], but actually taking care of your emotional and physical health can help you take even better care of [him/her]. It can help you be less stressed, more energetic, and have more patience. What do you do to take care of yourself?"</li> </ul>
<p>Encourage involvement</p>	<ul style="list-style-type: none"> <li>Encourage participation by suggesting possible activities, studies, and programs, where individuals can become involved</li> <li>Offer resource lists for ongoing research studies, local social programs, and patient organizations</li> </ul>	<ul style="list-style-type: none"> <li>"Some people find it helpful to be with others who understand what it's like to live with Alzheimer's disease, even if they aren't talking about the disease. Would you be open to participating in a local research study or meeting up with others?"</li> </ul>
<p>Abbreviation: MCI, mild cognitive impairment.</p>		

promote ageism, gerontophobia, and negative emotions.<sup>4,5</sup> Stereotypes about AD center on it being a chronic and debilitating neurodegenerative disease. They often focus on the later stages of disease when a person is most impaired and fully dependent for care in basic activities of daily living.<sup>4,5</sup>

When faced with a stereotype of the disease, persons living with dementia can feel threatened and worried about conforming to it.<sup>6</sup> In reaction, some can exhibit signs that confirm that stereotype. This phenomenon, termed *stereotyped threat*, can result in patients feeling distressed and exhibiting impairments worse than would be commensurate with the stage of disease. Stereotyped threat can hinder a person's functioning and quality of life. It can also interfere with clinical evaluation.<sup>2</sup>

Direct discussion that encourages reflection can help counter the effects of stereotypes. This discussion draws conscious awareness to stereotypes and can interfere with the influence of the stereotype by personalizing experiences. In turn, this may allow patients to identify stereotypes that are operating as well as the inaccuracies of those stereotypes.<sup>7</sup> Another feature present in stereotypes is conformity. In the case of stereotyped threat, individuals are conforming to an idea depicted in a stereotype. Interventions that validate the value of diversity can help individuals accept the ways they may not conform to norms and interrupt tendencies to conform. This could include language such as, "There is no one way to have AD. A person's experience can differ from what others might experience or expect, and that's okay."

### Ask Specific Tailored Questions About Beliefs, Concerns, and Experiences

Studies suggest that asking questions about a person's experiences, beliefs, and worries may help inform clinical assessment and identify knowledge gaps. Because the stigma of AD dementia can take many forms,<sup>2</sup> these questions should be specific to learn what the individual knows and feels about the disease.

Questions focused on a person's concerns may help identify opportunities to correct misinformation and enhance shared decision-making. A recent study with a small sample of 317 members of the general public showed the most common concerns about AD related to fears about discrimination.<sup>8</sup> More than half of those surveyed expected a person with mild-stage AD dementia to be excluded from medical decision making. Almost half (47%) expected data about AD in the medical record would lead to limits being placed on a person's health insurance. Neurologists and other clinicians may be able limit the consequences of AD stigma by directly talking about these commonly held concerns and, when possible, offering assurances. This may include question-statements such as, "Many people worry that a person will no longer be able to make his or her own medical decisions because of a diagnosis of AD. Is this something you worry about?" Describing for the patient when and how a capacity determination may be made, the

role of patient assent in medical decision making, and the ability of patients to dictate specific medical desires via a living will may help assuage concerns while also helping build trust and encouraging disclosure in patient-provider relationship.

It may be useful to address directly beliefs about the disease with patients and families when discussing disease course and establishing plans for disease management and health promotion. Believing AD is a mental illness has been shown to almost double the intensity of negative judgments about the severity of a person's symptoms.<sup>2</sup> This belief that a disease is a mental illness has been shown to place the locus of personal responsibility with the patient in ways that are detrimental, like that he or she is lazy for not adequately controlling or subverting symptoms.<sup>9</sup> In addition, beliefs about how a person's condition will worsen over time are strongly associated with stigmatizing reactions.<sup>2</sup> Patients or caregivers who ruminate about the prospects of future declines—to the omission of current abilities—may benefit from referral to psychotherapy services that improve tolerance for uncertainty and enhance mindfulness and present-focus.

Clinical inquiries may need to be tailored based on the characteristic of the individual.<sup>2</sup> Being older, female, or African American are sociodemographic markers of an elevated risk for developing AD dementia. They can also influence experiences of stigma that are associated with the disease. Individuals living with dementia must contend with both stereotypes about the disease and stereotypes about the social groups to which they belong. This tends to include stereotypes and beliefs about the competency and abilities of older adults. For women living with dementia, it can include additional stereotypes related to age-related losses of femininity and sexual power. Women are also often presumed the de facto caregiver upon diagnosis of a spouse or parent. This can place an onus on women who may not want or be able to care for a spouse. In addition, this presumed role can leave women vulnerable to lack of support and added stressors from the demands of caring for others in addition to tending to their own needs.

### Foster Dignity in Language

How AD is discussed, such as regarding its stages and prognosis, can affect the ways patients feel about themselves, what they expect of their futures, and the treatment they do or don't accept from others. Limiting stigma in health care communications hinges upon the use of language that respects the dignity of the individual.<sup>10,11</sup> It is critical to understand and intentionally shape the language used to talk about AD and what it means to live with a diagnosis.<sup>2</sup> There currently are no national language guidelines in the United States. However, guidelines offered by other countries, such as Australia, Canada, and Ireland, encourage the use of language that is accurate, respectful, inclusive, and empowering.<sup>11-13</sup> For example, referring to a patient as an individual living with dementia

or a person with dementia rather than as someone who is demented, is encouraged.

### Help Individuals Access Self-Care Strategies

In early stages of disease, patients often are aware of their diagnosis and so the stigma associated with it.<sup>2</sup> Stigma causes caregivers and family members to work harder than would otherwise be the case because they must manage the social consequences of the disease, such as taking steps to protect a loved one's dignity or social reputation. The added burden predisposes them to worse social and psychological outcomes.<sup>3</sup>

Helping patients and caregivers identify and engage in self-care may help mitigate the negative consequences of AD stigma. Self-care maintenance behaviors include illness prevention through a healthy lifestyle, illness behaviors like medication adherence, and proper hygiene practices. As part of mental hygiene, appropriate self-care includes creating positive moments and experiences. However, this aspect may be at risk for being overlooked within the other demands of caring for an individual with AD dementia. Reminding and encouraging patients and caregivers to strengthen their social relationships, enjoy emotionally positive experiences, and connect with their community may be particularly useful. Moreover, habits and preferences in self-care routines of older persons vary widely.<sup>14</sup> Engaging patients and caregivers to develop plans specific to their interests may increase adherence to these practices.

### Encourage Patients and Caregivers to Become Involved

The stigma of AD can be detrimental to a patient and caregiver's social support networks, leading to isolation and exclusion. Yet strong social relationships help protect against loneliness and depression. Neurologists can help patients and caregivers by offering local resource listings for opportunities to socialize and build community.

Patient organizations, such as the Alzheimer's Association ([www.alz.org](http://www.alz.org)) and memory centers and clinics offer listings for local support groups and programs. The Penn Memory Center at the University of Pennsylvania offers Dance for Health, a program that engages older adults in physical activity while also providing them opportunities for social connectedness; Typical Day, a photo-elicitation project that empowers older adults to tell their stories in order to raise awareness of living with cognitive impairment; and memory cafes where patients and caregivers gather, free of the labels of *patient* and *caregiver*, and enjoy food, music, and conversation.

### Conclusion

Neurologists and other clinicians can help patients and their caregivers address the stigma of AD. They may be able to limit or prevent harms like isolation and social withdrawal, interpersonal stress, depression, and loss of dignity. By asking focused and tailored questions, it is possible to challenge stereotypes

and so help patients personalize their experiences. In addition, this may enhance understanding of what patients, caregivers, and other family members believe about the disease. This may, in turn, help identify needs for education and anticipate pitfalls in patient-clinician relations. Moreover, inquiring about activities and offering resources to access self-care and become or stay engaged with one's community may aid patients by preventing isolation and improving stress management. ■

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