

How communities can fight the stigma that isolates people with dementia

10 May 2021, by Sienna Caspar



Isolation and segregation create and reinforce another kind of barrier to those with dementia: stigma. Credit: Shutterstock

Keeping people with dementia separated and secured is a common practice, based on the reasonable idea of safety first for the vulnerable. During this pandemic, however, contact with those in care homes, many of whom have dementia, was [cut off at great cost to residents' mental and physical health](#).

Isolation and segregation create and reinforce another kind of barrier to those with [dementia](#): that of [stigma](#), which can rob people of quality of life, personal agency and the dignity of risk the rest of the population expects as a birthright.

Research shows that experiencing stigma—defined as a mark of disgrace and humiliation—adds to feelings of social isolation, depression and [abandonment](#) among those with dementia. This stigma [exists worldwide](#), and trying to educate people at remove from those with dementia has not proved effective at reducing it.

One approach that might help diminish stigma is to build communities that are more welcoming and accepting to people with dementia.

Segregation is not the answer

The shame and fear associated with this stigma is so stubborn that people experiencing dementia still act on it, [to their own detriment](#). They wait too long to be diagnosed, losing valuable time, treatment options and [social support](#). Once labeled, they find that old friends, people in their community and even family members drift away. Caregivers also become more isolated.

Segregation for the sake of safety is not the answer to treating people with dementia—now numbering [50 million worldwide](#)—as fully human.

During my years as a certified therapeutic recreation specialist in North American [care homes](#), I saw how segregation led to stigma and blocked help for people with dementia. This is why now, as a professor in therapeutic recreation, I am engaging in research that focuses on a growing "[dementia-friendly](#)" movement.

This movement seeks to develop support systems for people with [memory loss](#), recognizing them as equals, celebrating their contributions and enabling them to live with purpose inside welcoming communities.

I teach my students that [personal relationships](#) are at the core of any therapy that aims to help individuals thrive as they age. To that end, I am exploring the possibilities for [contact theory](#), a promising, practical approach to combatting prejudice, to see if it can be applied to the stigma of dementia.

Contact theory posits that [personal contact enables and supports relationships](#) between majority and minority group members, and is [better at reducing stigma](#) than interventions that focus on education. Researchers have found that developing such relationships can reduce prejudice based on [mental illness, race, gender and age](#).

The ultimate goal, if contact theory works as it has elsewhere, is to extend the concept of age-friendly societies, as described by the [World Health Organization \(WHO\)](#), to include dementia-friendly societies.

"Dementia-friendly" communities

The WHO defines an age-friendly city as one that "encourages active aging by optimizing opportunities for health, participation and security in order to enhance quality of life as people age." However, a specific call to address stigma around aging and dementia—a double-whammy of discrimination—is not explicit in the WHO's approach.

Around the world, the WHO promotes and evaluates such things as walking programs, accessible transit and recreation facilities, housing options, health services and many senior-friendly activities to ease the potential hardships of aging and to promote inclusion. Access to these kinds of services should not disappear when memory does.

A dementia-friendly community would adapt physical and social aspects of an environment to ensure well-being and continuity of life for everyone. This would explicitly address stigma within the WHO's current framework. Related activities could help move communities worldwide from segregation to tolerance to true inclusion of all people as we age.

This is where the tenets of contact theory may prove beneficial. Recent initiatives show that finding ways to bring people with and without dementia together in support of the same goal can counteract the stigma of dementia. This type of activity helps move the "dementia friendly" concept from rhetoric to reality.

Examples include:

[University students living in seniors' housing](#) and spending time each week with their older neighbors in exchange for rent [Choirs that bring people with and without dementia](#) together in song Intergenerational programs that enable [school-aged children to develop relationships with long-](#)

[term care residents](#)

These initiatives result in people with dementia feeling included, valued and respected, and the creation of meaningful relationships for all.

Contact theory is not a perfect solution, and widening the world of people with dementia is not risk-free. For example, there is a risk of people with dementia [getting lost or going missing](#).

Despite these limitations, there is reason to feel optimistic that aging-friendly programs can be applied to dementia. I believe that if more people without memory loss interact and create friendships with those who have it, stigma will decrease. Adopting attitudes of inclusion based on [personal experiences](#) could result in friendlier, more equitable communities.

People with dementia cannot help forgetting. So it is up to us to remember that they are important members of society who deserve lives as connected and meaningful as our own.

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