

Challenging the Alzheimer's stigma

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The influential "World Alzheimer Report 2019: Attitudes to Dementia," issued by Alzheimer's Disease International, features input from Flinders Ph.D. candidate Jessica Young and Flinders researcher Associate Professor Christopher Lind.

The release of the report during World Alzheimer's Awareness Month serves as the major international spearhead during World Alzheimer's Month to raise awareness and challenge the [stigma](#) that surrounds dementia.

[The report](#) describes the findings of a huge worldwide survey, with almost 70,000 respondents from across 155 countries.

The survey reveals that 95 percent of participants think they could develop dementia in their lifetime, and that two in three people still think that dementia is a normal part of aging, while 62 percent of healthcare practitioners still think dementia is a normal part of aging. More than 50 percent of healthcare practitioners surveyed agree that their own colleagues ignore people living with dementia, and 33 percent of people thought that if they had dementia, they would not be listened to by health professionals.

While someone in the world develops dementia every three seconds, thorough understanding of the disease is scant; one in five people attribute dementia to bad luck, almost 10 percent to God's will and 2 percent to witchcraft.

With their Canadian colleague Professor JB Orange, Jessica Young and Associate Professor Christopher Lind co-authored the opening chapter of the global report, entitled "What is stigma?" In this chapter, the authors introduce concept of stigma as a [social phenomenon](#), describe its relationship to the concepts of stereotype, prejudice, discrimination and power, and offer some initial recommendations to reduce dementia-related stigma.

"We were very privileged to be invited to contribute to this powerful report," says Jessica, who has recently published papers about the stigma attached to dementia.

Jessica's recent works include a qualitative systematic review that relates to transitions in care and highlights how to support people with dementia being involved in these decisions, published in the journal *Dementia*.

This review challenges common stereotypes of people with dementia as passive recipients of care, or as unable to be involved in decision-making about their own care.

She also recently published a theoretical paper in the *Journal of Aging Studies* that expands current understandings of social injustice for people with dementia and looks at the experience of dementia from a human rights perspective.

"My Ph.D. research continues to delve deeper into these concepts of stigma and justice" says Jessica. "I have interviewed people with dementia and their families about transitions to long-term care, with a view to exploring issues of power, injustice and prejudice throughout the care continuum."

For Jessica, contribution to the report represents a valuable opportunity to continue to advocate for full and equitable engagement of persons with dementia in our communities.

"It is encouraging to me to see how my local research contributes to a broader, global discussion about how people with dementia experience the world, and how we as a community might best support them," she says.

"'The World Alzheimer Report 2019' is a really encouraging springboard for necessary global change. It offers some really valuable, practical recommendations to begin to reduce dementia-related stigma, to ensure persons with [dementia](#) are valued, included and treated with due respect."

More information: World Alzheimer Report 2019 (PDF 160 pages):
www.alz.co.uk/research/WorldAlzheimerReport2019.pdf

Provided by Flinders University

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