

# Dementia and self-harm: Why it's crucial to support patients in first year after diagnosis

May 2 2023, by Lachlan Gilbert

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Credit: AI-generated image ([disclaimer](#))

People diagnosed with dementia are more likely to self-harm within the first six to 12 months after initial diagnosis, highlighting the need for health services to offer more follow-up support in this crucial period.

In what is believed to be the largest study of its kind, researchers with

expertise in medicine, psychiatry and psychology at UNSW Sydney looked at NSW hospital data captured for more than 180,000 people admitted to hospital between 2001 and 2015.

The researchers analyzed statistics relating to two cohorts of patients admitted to hospital: 154,811 people recorded as having dementia, and 28,972 people admitted for [self-harm](#) injuries. The findings were reported in the paper published May 1 in the journal *Alzheimer's & Dementia*.

UNSW Medicine & Health's Dr. Adrian Walker, who was the study lead author, says while smaller studies and anecdotal evidence had previously suggested a link between dementia diagnoses and self-harm, the NSW hospital data supports the findings in a large population setting.

"We were interested in finding people who came to those [health services](#) and had been diagnosed with dementia to see if we could find out, what are the rates and predictors of self-harm among people living with dementia?" Dr. Walker says.

"We know that that's an important question because dementia itself is associated with not only a lot of neurological changes, but also a lot of grief and a lot of anxiety. And it can create this perfect storm of factors that may contribute to self-harm."

## **Drilling into the data**

When the researchers examined the data, they saw that of the people recorded as having dementia by health services (hospitals and outpatient facilities), 692 of them went on to be readmitted to hospital for self-harm.

Women accounted for the majority of both people initially admitted to

hospital with dementia (60%) and initially admitted because of self-harm (53%). But when researchers looked at the number of people who went on to self-harm after being admitted initially with dementia, the ratios between the sexes flipped, with men making up 60% of those admissions.

"Generally, women tend to be over-represented in people diagnosed with dementia, as well as people who self-harm, compared to men," says Dr. Walker.

"The fact that there are more men at the intersection of self-harm and dementia is concerning, though we should also be careful not to forget the substantial number of women living with dementia who self-harm."

And when the researchers drilled down further into those numbers, the episodes of self-harm for both men and women appeared alarmingly soon, within 12 months of the first hospital visit for dementia.

Scientia Associate Professor Simone Reppermund is a psychologist with UNSW's Department of Developmental Disability Neuropsychiatry and supervising author of the study. She says the figures suggest health services, including [primary care physicians](#), should view dementia diagnoses with a new sense of urgency.

"The message to clinicians and indeed, the outside world, is that it is really important, once a person gets a diagnosis of dementia, that psychosocial and mental health supports are kicking in straight away," she says.

"We would like to see people who are initially diagnosed to get the support very early on to prevent self-harm and suicide later on. Even without dementia, men 85 and over are in the age group with the highest age-specific suicide rates, so it's doubly important we offer extra care

for people diagnosed with dementia."

## **Lived experience**

The researchers also spoke with a number of advocates, some of them living with dementia and others who were caregivers. Mr. Stephen Grady was one of the advocates with lived experience of dementia and spoke of his own reaction when he was first diagnosed at the relatively young age of 60 while enjoying a successful career as a measurement scientist.

"So here was me as a very high functioning member of society, one of the leading people in my field," Mr. Grady says.

"And then suddenly after being diagnosed, it felt like I went from a valuable contributor to society to having no value at all. So, there's this whole question of, okay, 'Is your life over, is it still worth living?' These are the kinds of questions that I believe a lot of us ask ourselves, but it's only when you find the value in your life again, that you can refute them."

Mr. Grady, now 68, says the hospital data confirms what he has long known anecdotally as an advocate for people living with dementia: that the first 12 months after diagnosis are crucial.

## **Is self-harm a precursor to dementia?**

The researchers also looked for evidence of a reverse trajectory—how many people, with no history of dementia, went on to develop dementia after being first admitted because of self-harm?

They saw a similar story to the path from dementia to self-harm: again it was more men—475, or 55% of all those previously admitted for self-

harm—who went on to develop dementia. But with 395 women who traveled the same path from self-harm to dementia diagnosis, it is clear that this is an issue affecting both sexes.

"At this stage, we should also be careful not to read too closely into the causal relationship between self-harm and dementia," says Dr. Walker.

"Whether self-harm might lead to dementia, or dementia might lead to self-harm, is still an open question. Indeed, it could be both, and it could also be neither—there could be something else going on. But what is clear in the numbers is that the two are linked."

Other findings of the research were:

- Those living with dementia who self-harmed tended to be younger at their initial dementia diagnosis than those with no record of self-harm.
- Being divorced, widowed or separated predicted a lower likelihood for people with dementia to present to hospital for self-harm than those that were still living with a partner.
- People living with dementia with complex psychiatric profiles also had a higher risk of presenting to [hospital](#) for self-harm.

The research team plans to extend these findings by drilling deeper into the health outcomes for people living with dementia who self-harmed. Specifically, they are interested in how health service use impacts self-harm.

"Self-harm indicates substantial mental health distress, so it would be good to know how mental health services respond to self-harm in people living with [dementia](#)," says Dr. Walker.

**More information:** Adrian R. Walker et al, Risk factors for dementia

and self-harm: A linkage study, *Alzheimer's & Dementia* (2023). DOI: [10.1002/alz.13080](https://doi.org/10.1002/alz.13080)

Provided by University of New South Wales

Citation: Dementia and self-harm: Why it's crucial to support patients in first year after diagnosis (2023, May 2) retrieved 4 May 2024 from <https://medicalxpress.com/news/2023-05-dementia-self-harm-crucial-patients-year.html>

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