

Congress of Older People's Voices from the Margins

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Dementia, masculinity and self-harm, by Steve Grady

The misconception about people living with dementia is that we turn into raving lunatics and become abusive and do strange things until we turn into a vegetable or become silent. That's not how it is, but that misconception affects how we respond to the diagnosis of dementia. I also want people to know that our responses to dementia diagnosis are shaped by our gender.

For many older men, their idea of self is wound up around their work. What they are able to do helps to define who they are. I was fairly important in Australian measurement science and then I was diagnosed with dementia, and I couldn't do it anymore. I couldn't do all the things that I used to do that made me feel like a man.

Most men are the major bread winners in the family. Suddenly that's taken away from you. The doctor can say you are no longer able to work. You need to take early retirement. It's a big struggle for us to adjust to that.

One of my male friends who was diagnosed with dementia felt he couldn't talk to his wife and children about it. He couldn't talk to his church friends about it. He couldn't cope with it. He came from a society where the man is important. He banned his wife from talking about it. He wouldn't talk to his children. I think he was ashamed that he was no longer the strong man that society expected him to be. Now he is dependent on his wife, he can't play soccer with his children; he found that difficult. So, he tried to hide it from everyone.

The silence and shame is bound up with our concept of who we are as men, we are the bread winners. Nowadays men can feel more confident letting their wife go out to be the bread winner, but often the man is still the head of the household. That's the role we play in a patriarchal society; I know that isn't equal, but I want you to understand what it is like for some older men. One moment it is there and then suddenly it's gone.

Some men see the diagnosis of dementia as the loss of their position of power and influence. They have lost their health and then their power. The loss of health is the knowing that dementia is a progressive illness. The loss of power is the responses of others to the diagnosis of dementia. Our human rights are taken away and our role as men changes. Some men feel helpless. We lose our concept of self, but we have to adapt to those changes.

When I was first diagnosed, I was told it was no longer safe for me to play with electricity. I knew what was safe and what wasn't. But my neurologist had a blanket view; I had to stop.

These things that are taken away can devastate us. Our drivers' licenses are taken away and people try to wrap us in cotton wool. That can feel very restrictive.

In a world where shame and stigma mean we feel we can't talk about the diagnosis of dementia, and we can't talk about the changes to our perceptions of who we are as men, that's when self-harm happens. Some people don't get help when they are diagnosed, and they left to their own devices. I was okay initially and then I wanted to die.

Some men try to kill themselves, or self-harm with drug or alcohol abuse due to loss of health and masculinity. Some people can embrace it, they are flexible in their thinking about who they are. Some men are more rigid and shut down and then don't know what to do.

I have been involved in research where we looked at emergency department admission for people who had attempted suicide after dementia diagnosis. It showed self-harm was more prevalent in men in the 6-12 months after diagnosis. It also showed that when they get referred to mental health services, the prevalence of self-harm decreases.

The moral of the story is to get the support in the first place. My neurologist told me to go home and get my financial affairs in order and come back for a review in six months. There was no referral to a help line, or Dementia Australia. I needed support and so did my wife.

I went into a grieving process; I wouldn't talk about it. I was angry, till finally I came to a point of acceptance. Meeting other people going through what I was going through helped me to understand what I was experiencing.

So many people won't use the D-word, but dementia is not a shameful word. It's the attitudes of others that creates the stigma. People don't see us as living good lives, and so it can be difficult for us to see that as well.

Practitioners need to ask about what we are experiencing and link us in to support services. They need to understand that people living with dementia have gender and our gender influences the ways we respond to dementia. It is ageist to think we are genderless.

What's one thing people can do now? If you are a person living with dementia, confront your fears. The earlier you get diagnosis the earlier you can get support.

If you are a service provider, ask us if dementia has changed the way we feel or express our gender. Then ask us what support we need.