

## Congress of Older People's Voices from the Margins

This story was documented for the #Embolden2023 *Congress of Older People's Voices from the Margins*. A full report on Congress is available at [celebrateageing.com/margins](https://celebrateageing.com/margins)

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### Men who care, by Dubhg Taylor

Hello, my name is Dubhg Taylor, and I am a retired social worker and now full-time care partner to my wife, Eileen who lives with younger onset dementia.

All relationships naturally change with time. One significant change is if one partner develops a debilitating illness such as a dementia. Dementia brings increased physical and emotional distress which can have a massive impact on even the strongest relationship. Sadly, there is little acknowledgment of the ways it affects care partners. And this paper is specifically addressing the topic of male care partners and the issue of intimacy.

I want to share with you some insights I have gained personally and from talking to other men who are care partners of a person living with dementia.

Some men with a female partner who is no longer sexually interested may believe this is a reflection on their manhood and this can be a barrier to them talking to service providers about it. They may also be struggling with the issue of sexual consent; if their female partner is unresponsive, how do they know when to persist or how to negotiate sexual consent?

Male carers may be embarrassed or afraid to talk about what they are experiencing. It may feel too private or scary talking to a health practitioner, it's quite different to speaking with your mates over a pint of beer at the pub.

The consequence of this situation is that one can feel lonely and frustrated and confused. How do we manage these situations? Typically, the biggest thing is loneliness. For example, I like to engage with other people in ways where we can have deep and meaningful conversations.

In my own relationship I miss that form of intimacy the most. Now it's all about household chores and the physical care I need to provide. I am kept busy doing

much of the cooking and laundry and it's up to me to keep the place clean and tidy. It seems there is a never-ending cycle of engaging in the things that need to be done for both of us. And I am certainly no martyr.

Another issue for us had been after the diagnosis of dementia that many families and friends didn't contact us like they used to. Lots of them simply backed away. They claim they don't know how to engage with a person living with dementia. A common imagine of many is seeing people in the later stages of dementia, but my wife is not. Nevertheless, people find it awkward to communicate with her; they don't understand.

People think dementia means you have a mental illness, and they don't know how to deal with it so they back away. That contributes to a lot of isolation for us both.

For example, in the past we would have friends to dinner and play cards till the late hours. That doesn't happen anymore. Now, it's more about a continual process of juggling loneliness and time. Fortunately, one thing that keeps me reasonably sane is being able to play in a local band as a drummer. Also teaching a weekly class at a local college, managing our local Dementia Alliance's Memory café, chairing the alliance's committee, and going to the supermarket. Busy, but very lonely.

I know of some men who have chosen to find intimacy through a new relationship outside of their marriage, sometimes with the support of their partner. It's not something I would do.

For me intimacy is about connection to others, deeper thoughts and conversations and feeling accepted and understood. Sexual activity can be part of that, but it doesn't have to be. For me it's more about emotional closeness.

I know these challenges are not unique to men, I've no doubt that women experience them as well. But my guess is that at least women are more likely to talk about it with their girlfriends. That makes a difference. It would make a difference to me. I did have a close male friend that I could talk with and over a coffee, but sadly he died two years ago. Right now, with male acquaintances it is more low key social "work" chat.

I think many older men have been socialised to be that way, you don't talk about your feelings; along with the belief that "Big boys don't cry." It's not easy to overcome that conditioning.

About a year and a half ago, there was a program run by Dementia Australia for male carers, called *Blokes Who Care*, which was wonderful. Sadly, it didn't last long. We need to expand on this to form connections to help each other. We need to have carer groups for male carers to discuss issues that affect us, and we need to support each other. In mixed carer groups the men stay silent. I could set up a group like this, but unfortunately, I don't have the time. With the right men and support it could be enormously useful.

If you are hearing this and you know a male who is a care partner, let him know this: “You are still a man.” If your partner has dementia and their sexual interest or intimacy changes due to dementia; “It’s the dementia that has caused that, not your masculinity. You are still a man.”

Thanks for listening.