

Negotiating intimacy and sexual consent for people living with dementia, Theresa Flavin

Philippa Campbell Fellowship, Elder Leadership Academy

Title: Negotiating intimacy and sexual consent for people living with dementia

Fellow: Theresa Flavin

Date: 2023 – current

About the Philippa Campbell Fellowship

The Philippa Campbell Fellowship was launched in October 2013 and is awarded annually to older women working to combat the inequalities faced by older women. The Fellowship sits within the Elder Leadership Academy. The Fellowship honours the life and contributions of Phillipa Campbell, a passionate feminist, gerontologist and former CEO of Elder Rights Advocacy, Victoria.

Context

Currently in 2023 over half a million people in Australia live with diagnosed dementia. Countless others live with undiagnosed and emerging symptoms. All of us live alongside this disease as best we can, however an under recognised aspect of dementia is the impact on intimate relationships and sexual activity.

This can present in a number of ways and impact both the person living with dementia, their intimate partners as well as family members and paid carers for example:

Hypersexuality is often a feature of fronto temporal dementia but can present in other dementia types. The increased desire for sexual satisfaction intersects with a decreased awareness or insight into the importance of the affirmative consent of the intimate partner. In the context of older persons, this can often result in repeated sexual assault, physical and emotional trauma, and eventual ‘placement’ of the partner living with dementia into residential care.

Alternatively, due to social and cultural pressure, the situation may not be actively addressed, and the abuse continues until the person living with dementia eventually reaches a stage of dementia where they become unable to physically act on their responses.

Loss of sexual appetite is an equally common feature of dementia, which can be difficult for the intimate partner to accept. This dynamic unfortunately can also present as sexual assault as the partner who retains the desire may not consider active consent to be important or necessary. Anecdotally this situation is reasonably common in the community, where predominantly older women living with dementia present at memory and GP clinics with genital injury consistent with sexual assault.

However, the older woman is often accompanied to these appointments by the potential perpetrator. In the absence of any federal adult safeguarding networks, the health professional is unable to intervene.

In the residential aged care setting, older adults are grouped, often locked in together based on their diagnosis of dementia, but with little or no regard to their stage of disease or personal wishes in relation to companionship or sexual preferences.

Hypersexual people who are generally physically active are locked in with non-sexual people who are often physically frail. This of course results in not only violent attacks, but rape and sexual assault of the less dominant older person. In the perceived absence of the older persons voice, consent is generally presumed to have been given, as nobody seemed to hear a loud 'no'.

Affirmative consent has not yet reached residential aged care, and the older person may not have any say in whether they wish to enter into sexual activity with other residents. If a resident chooses not to participate, they may not be supported to maintain these wishes.

I contend that there is a pressing need for a pathway to hear the voice of the person living with dementia into the future - through the platform of an advance social directive. This directive would cover matters that are important to the older person, as cognitive function declines. The directive could include:

- family of choice
- cultural, spiritual and religious matters
- lifestyle
- intimacy and sexual activity.

If these wishes could be documented, and more importantly, provide the basis for the people in our lives who care for us to support these wishes, we might have a little more hope for the future.

Presently, outside of the advance care directive (which may or may not dictate health care after capacity wanes), our wills (which may or may not choose where our financial assets are distributed after our death), and a power of attorney (which nominates someone to make decisions for us when we can no longer communicate), we have **too little** input into the future when our minds have transitioned but our bodies remain at the mercy of people who do not know us.

There is also much work to be done to assist people living with dementia and our care partners to understand the impact of dementia on sexuality, so that we can begin to make plans on how to manage future stages of the disease. This education must also include a means to protect **our** privacy.

Aim and objectives

The aim of the Fellowship is to promote increased awareness and understanding of the necessity for affirmative sexual consent in intimate relationships when one person in the relationship is living with dementia. This will be achieved by developing

resources and providing education for people living with dementia and their intimate partners.

Process

The Fellowship process is unique. The project design, implementation and evaluation will be co-led by me – Theresa Flavin, a person living with dementia. This is considered critical to the effectiveness of the resource developed and the education delivered – as well as the success of the project.

Activities

1. Consult people living with dementia about their experiences and needs, for example:
 - a. Consultation with people living with dementia
 - b. A survey of people living with dementia
 - c. Discussion in groups of people living with dementia
2. Draft a resource for people living with dementia that includes practical strategies for negotiating sexual consent
3. Seek feedback from people living with dementia and their intimate partners about the resource
4. Deliver education about the resource for people living with dementia and their intimate partners
5. Deliver education for service providers on using the resource.

Outputs

- A brief report on consultation with people living with dementia and their intimate partners
- A resource for people living with dementia and their intimate partners
- An advanced social directive that includes intimacy, sexuality and sexual consent
- An online education session for people living with dementia
- An online education session for service providers.

Outcomes

The key outcome is the development of a resource to promote understanding of not only the legal requirements for affirmative consent from all partners in all sexual encounters, but in particular when one partner lives with dementia.

This resource will include practical examples and suggested interventions when changes occur and include some conversation starters for anyone who chooses to reach out for assistance. The resource will also include examples of strategies suggested by people living with dementia and their intimate partners that have had a positive impact on their relationship, but also include pathways for support when a situation escalates such as urgent respite and DBMAS services.

While currently there is no adult safeguarding program across Australia, The states that do have this program in place will be identified. The resource will not be written

with a view to police intervention, however there are times when this may be appropriate.

The resource will also include suggestions on reaching out for assistance while ensuring the privacy of all parties. In other words, many older people do not reach out for assistance as they are dependent on the perpetrator for housing security and care. Ways to circumvent unintended consequences will be explored with the various support organisations.

Partnerships and acknowledgements

- A project support network will be established with a call out for individuals, groups and services to help promote the success of the project
- We will seek the support of Dementia Alliance International and OPAN's National Older Person's Reference Group.

Links: tbc
