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Building respect for older people

Congress of Older People's Voices from the Margins

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Sexual consent in the context of dementia, by Theresa Flavin

While sexuality is as individual as the stars in the sky, there are a few common themes, the most fundamental of which is mutual consent. In days gone by, sexual consent was not specifically required from a woman. Thankfully our society here has evolved to recognise and support the rights of all persons to say yes or to say no. This is enshrined in affirmative consent laws; however, these changes have been heavily targeted to people in their child bearing years, with little or no effort to reach and educate our older people.

In the context of relationships where one or both partners lives with dementia, there is often a marked difference in levels of sexual interest and willingness. For example, a person living with dementia may become hypersexual, sexually demanding and incapable of respecting a 'no' response. This will often result in repeated rape of the more sexually vulnerable partner. It's not uncommon for the less interested partner to use sexual activity as a way to placate the more interested partner in order to avoid violence.

On the other hand, when the less dominant partner lives with dementia, it's also quite common for the more dominant partner to continue sexual activity in the absence of consent. Resulting in physical and emotional damage which goes unacknowledged.

In residential age care, where people living with dementia are grouped according to their disability as opposed to their wishes and preferences, more dominant and sexually demonstrative people without the insight to respect or request consent assault other more vulnerable residents and staff. Resident on resident sexual assault is not well managed, as the nexus between respecting the human right to sexual expression and respecting the right to say no becomes cloudy. Residents are expected to vociferously object, shout and behave in ways that society expects a

rape victim to behave in order to demonstrate that they do not consent, otherwise the activity is considered consensual. A pretty unsatisfactory outcome for a frail older person who is no longer verbal.

Well, thanks to the Older Persons Advocacy Network and Dementia Alliance International, the #ReadyToListen Dementia and Sexual Assault Special Interest Group led by Catherine Barrett and Kate Swaffer have worked with a team of people living with dementia and some care partners to begin the process of taking sexual assault of and by people living with dementia out of the shadows and developing some resources for residential age care and the larger community. Knowledge is power, and when an older person understands what is acceptable, what is not acceptable, what their human rights are and what recourse they have to defend them, things will begin to change.

The United Nations Open Ended Working Group is in the process of developing a Convention for the Rights of Older Persons. This will elevate the human rights of older persons to the same level as everyone else in the community and will entitle us to the same level of support.

When we think of the difficulty managing sexual interaction involving a person living with dementia, whether in the context of being a perpetrator or a victim of sexual assault or unwanted sexual contact, we wonder what we can do about it. How can we manage this? How can we protect them?

Well from my perspective these questions miss the point entirely as these questions assume the person living with dementia is not entitled to a voice in the conversation. These questions simply perpetuate the paternalistic attitudes that trap us in systems and processes to ultimately incarcerate us.

I would suggest that a number of things change in order to actually allow us some personal autonomy in our sex lives into the future, when we may no longer have the means or capacity to consent or respect the wishes of the other partner.

1. Co designed education or at least awareness information on potential changes to the intimate relationship as a result of a dementia diagnosis. This must outline the rights and responsibilities of each partner to negotiate sexual activity in a mutually safe, respectful and legal manner

2. Development of a pathway for any person to write an ‘advance social directive’ which is private from family members, but available to appropriate organisations such as police, medical staff and senior practitioners. This directive, which could be made on video or uploaded to My Health record, would not only facilitate an advance sexual directive which would guide service providers on the wishes of a person after they lost capacity to defend their wishes, but would also greatly enhance ‘person led care’, and supported decision /substitute decision making processes

3. Mandatory acknowledgement: currently from my informal discussions with staff at medical practices and memory clinics, hundreds of older – mainly frail women are treated for significant genital injury every month. There is no reporting pathway for these professionals, the perpetrator is usually the older person's guardian, and is usually in the examination room. There is no recourse for the older person or the treating professional, as the expectation is that the 'guardian' investigates Elder Abuse, but this is a conflict of interest in most cases. Australia urgently needs a federally organised adult safeguarding scheme in order to facilitate support and services including respite

4. Trauma informed care. Many, many older women have experienced a lifetime of abuse and violence. It forms part of who they are, and disclosure at any time would have resulted in loss of housing, children, wider family etc etc. This also leads to culturally aware care and choice. Currently it is not possible for an older person to specify same sex residential care, or the sex of their care workers. The intersection of employment law, gender discrimination law and human rights obligations works against the needs of many older people who have lived extreme trauma and abuse. We need to find a workable way through this in order to provide a safe older life for our elders.

While the above suggestions are necessary and are most certainly in need of development in order to account for all of our diverse needs and wishes, there are a few things we can all do in our own lives while we advocate for bigger stronger systemic change.

Consider your own intimate relationships. If dementia affected you, how would you want your partner to manage sexual activity? In my private life, I've found that if I have sex, my mind gets untethered from time and space. The physical actions take me to a time of child sexual abuse and its simply horrible. My partner and I have found that 'process consent', where he checks in with me every few minutes to make sure I'm 'with him', keeps us both safe from those memories. This is not very spontaneous, and definitely interrupts the flow of the activity, but in my partner's words 'I don't want to make love to the 12 year old frightened girl, I don't want to make love to your body while your mind hides, I want to make love to you, and if you can't, well then we do something else'.

Consider the resources developed by the #ReadyToListen Dementia and Sexual Assault Special Interest Group. Think about them in the context of your work. Could they be adapted? Could they be improved? Can your business consider a sexual health policy that includes the individual wishes and preferences of each individual older person and supports them in those wishes and preferences as opposed to a blanket ban on sexual activity or asking adult children for permission for the older person to have a sexual experience.

Consider the role of specialist sex workers, pornography or other aids that may assist in the older person expressing their sexuality without the risk of imposing on another's human rights.

I’m only beginning this conversation. Many of the solutions are in your heads and hearts, but if you take away one thing from what I’m saying, let it be that the voice of the older person is what matters most, and whatever means we can employ to have that voice carried into the future and respected is the best and fairest way to go.