

Intimacy, Consent and Dementia
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My name is Theresa Flavin. I was diagnosed with younger onset dementia when I was in my mid forties. I was fortunate to be diagnosed very early in the disease process, and this has given me the gift of having some time both to adjust to my new brain, and to examine the effects of dementia on my life and express these effects in a way that others can understand.

At diagnosis, like most people, the focus of those around me was on 'getting my affairs in order'. This was focused around my money, and how I would like to die, but there was nothing for the 'in between'. The pervading feeling was that I should patiently and quietly wait for the end. This perception of course completely removed any light or joy from the time I had left, as I felt like the proverbial 'oxygen thief' just using resources without contributing anything.

Those concerns aside, it became apparent over time that dementia was much, much, more than a loss of memory. In fact my memory in general was ok, it was the functioning of daily life that I could no longer manage well.

I've come here today to share one of these functional challenges related to intimacy - and what we can learn from my experience.

We know from statistics from the Aged Care Royal Commission that there are about 50 sexual assaults in residential care every week in Australia. By sexual assault I mean '*unlawful sexual contact, or inappropriate sexual conduct*' – but most people can't remember that term, whether they've got dementia or not. But even more shocking to me is the fact that staff believe that in 58% of these assaults, there was no ill effect on the victim. I have no words to describe my disgust at this ignorance, so I will continue...

I haven't found any statistics relating to sexual assault of people living with dementia in the community, however anecdotally this is not uncommon. This may be due to the legacies of marital rape immunity laws. We also know there is a problem with sexual assault of older people by their intimate partner living with dementia who is sexually disinhibited or hypersexual.

To say that there are no negative effects of sexual assault, is really saying that the victim is not displaying the emotions you expect to your satisfaction. This is unacceptable. There is no other disability where this lack of education would be tolerated. There is always harm from sexual assault, and we should not have to be giving you behavioural clues, we expect you to have the education and professionalism to already know this.

When I think into the future about when I might need residential care I feel scared and vulnerable. Will I be one of the 58% that are just left to live with unwanted sexual attention? Will staff assume that I 'wanted it' because I didn't say no? Are we really saying these words in 2022?

What about all of us who are fortunate enough to stay at home? Will a lifetime of family violence simply continue unchecked because we can no longer say no, or because we don't know that family violence and sexual assault services are for us as well.

Sexual consent is critical at any time in our lives. It doesn't become less important as we get older. However, when I can no longer communicate either at home or in residential care, who is going to be listening or caring if I consent or not? Who will protect me from unwanted sexual encounters, and who will protect me from making unwanted advances if I no longer know what I am doing? How can I maintain my human and legal right to sexual consent and my responsibility to give or withhold consent, and my responsibility to respect other people's choices?

Even people living with dementia are entitled to intimacy. It's a human right, but also a human responsibility. So what happens when we want to exercise our rights, but don't have the capacity to take responsibility to understand sexual consent, or lack of consent? Well, to me it's the same thing. The right to intimacy is inextricable with the responsibility to respect someone else's right to say no.

What can service providers, health professionals, couples and families do?

There are many things residential aged care service providers can do to promote sexual consent for people living with dementia. It must begin at diagnosis, setting out the changing nature of relationships, the changing legal context of consent, and co-development of services and resources to help navigate these changes. People living with dementia in their own homes also need to be given information about sexual consent.

Change your partnership dynamic

I've learned from having dementia that I have changed from a thinking woman with feelings, to a feeling woman with thoughts. I've spoken with many other people living with dementia and they have had similar experiences. Our signposts and cues for life have gradually changed from learned behaviour to responsive behaviours, based on our feelings and emotions. As the disease progresses, this change increases.

My husband and I have a respectful and fulfilling relationship, however I was finding that I was increasingly reluctant to be intimate. I had feelings of resentment, revulsion, fear, panic, nausea and could not find any reason - so I carried on without listening. Eventually, at a very personal time, I had a very extreme response. I was crying, shaking and extremely upset. He couldn't understand. He had not hurt me.

As a young girl, I was sexually abused by an older man for a number of years. I had buried this and rarely gave it thought, but now in the present, my husband is the same age as the perpetrator. My mind had taken me back in time, and I truly felt like it was happening again. My ability to separate the past and the present subconsciously was gone. This was not only a traumatic episode, it was further compounded by the realisation that I had reached a new stage in the dementia journey.

When my eyes were closed, and I was in a place of emotional and physical intimacy, I didn't have the visual and audio cues which keep me tethered to time.

However, something good came from this horrible experience. My husband and I had to take a fresh look at how we relate to each other, and consent will never, ever be taken for granted again by us. We have implemented a clumsy but effective system of process consent, where he constantly checks in and makes sure I'm with him and that I'm ok. Sure it's not very spontaneous, but this respect has helped me build trust.

Now my purpose in sharing this experience is not to elicit compassion or emotion, but to show you that even when a person is living with dementia, our feelings and emotions are fully intact. We experience everything inside, even more than everyone else. The only difference is that these emotions are generated inside of us and not necessarily in response to what is happening in real time.

Over time it becomes more difficult to relate feelings to events past or present. You are stuck with the feeling with no way to rationalise it away.

The good news is, that if we are made aware that these changes are in our future, we can prepare and change how we relate and engage with our intimate partners over the course of the disease. Concepts such as process consent, negotiation and consistent checking in are valuable ways to maintain mutual respect and true consent.

I really wish that my husband and I had some practical knowledge of how dementia could impact our relationship in the future, and how we might consider navigating this. The information on sexual consent out there in internet land is very medical orientated. This is useful but only step one in learning as a family how to live alongside dementia. Changes in sexuality are mentioned as being a 'thing' but the information comes to a dead end. No practical examples, no pathways to support or help, so inertia sets in and you just wait for life to be over. Imagine a world where partners could discuss these private and sensitive matters with a trained professional, helping both parties understand their changing needs and responsibilities, and helping put individual advanced sexual and social directives into place that would be accessible into the future.

The Charter of Sexual Rights and Responsibilities

In 2022 the #ReadyToListen project developed a Charter of Sexual Rights and Responsibilities in Residential Aged care. The Charter is a good start to guide staff. However, if staff don't take into account the wishes of the resident – its just noise.

We would really like to be consulted about our wishes. Just as you ask all the questions for consumer centred care, maybe consider privately asking the individual about their wishes in relation to sex. When they can no longer consent or can no longer understand their sexual responsibilities – what do they want? Staff should discuss this with residents, and sometimes they might need to make sure the residents partner is not present.

Having the resident's wishes documented formally will empower staff to protect us from ourselves and from others. This will preserve our dignity and the memory of the person we were. Most men living with dementia I've spoken to are horrified at the

thought that they might become a 'sex pest' and deeply want to protect themselves and others. Applying the Charter of Sexual Rights and Responsibilities to our care could give all of us some certainty that you will ask us what we want, and that you will try to make sure we are safe from ourselves and others.

Sexual consent is included in the Charter. Affirmative consent is important– and its more than the absence of yes means no. Staff need to make sure there is free agreement. This means making sure the resident is not being coerced or isn't mistaking the identity of their sexual partner or the nature of the sexual act. Staff need to make it clear how decisions about sexual consent are made and who makes them.

Advanced Life Directive

A Charter of Sexual Rights and Responsibilities is worthwhile, but it must be supported at the individual level. Where possible, private conversations must be had with the older person, by someone well versed in supported decision making in order to develop an individualised sexual directive for when the ability to willingly consent is uncertain.

This is of course important in the community too, we focus so much on 'getting our affairs in order' which focuses on assets and the medical aspects of our future, but no formal way to record our wishes and preferences about how to live in the 'in between time'. I propose that the Department of Health open a portal to either myhealthrecord or myagecare, where we can record our social preferences, including trauma triggers and our wishes for sexual activity in the event that our ability to advocate for ourselves is diminished. Along with the advanced care directive, this needs to be digital and available with consent to health providers where it is relevant. Writing our wishing on a bit of paper in a box at the bottom of the wardrobe is exactly as useful as a bit of paper in a wardrobe in the moment.

Education

Staff are always encouraged to do more training, but it would be so valuable and empowering if people living with dementia and older people were also educated to some degree. The laws and community values around sexual consent have changed over time, and these changes are so empowering, especially for older women, but nobody is telling us. Please consider sharing empowering information and education with your residents, clients and patients and help them contribute to their own sexual safety.

Report - always

When a sexual assault occurs, there is no question that there is harm to the victim. This is a given, and how the victim displays their pain bears no relationship to the action that must be taken. Sexual assault must always be reported to the Serious Incident Response Scheme (SIRS) as a Priority 1 incident. We also need to clarify reporting sexual assault of residents while they are on home leave and older people and people living with dementia who are living at home and experiencing sexual assault.

A referral pathway

Older people and those living with dementia in their own homes are particularly vulnerable to sexual assault. They may be reluctant and fearful to report abuse. Reporting the life partner for example may put an older person at risk of further abuse, recrimination, disbelief and potentially being placed in residential care. This is a tremendous and valid barrier to reaching out for help.

We need to explain to older men, that saying yes once at the marriage altar does not entitle you to sexual relations without consent. We need to educate older women that they do have the power to say no, and that they can access respite care if their wishes are not respected. Family violence and sexual abuse does not stop when people reach 65 years of age.

I propose that health and care professionals develop a referral scheme when it is apparent that an older person or person living with dementia has been sexually assaulted. This referral scheme could be accessed GP, the OT, the chiro, the geriatrician, the memory clinic. Calling the police may place the older person at further risk of abuse and homelessness. Lets create a pathway here, so service providers understand how to help. Lets talk about what could possibly help.

Trauma informed care

The community including health and care staff need to understand that so many older people have experienced trauma – whether they have told you about it or not. If a person with dementia says they have been sexually assaulted in residential aged care, that does not automatically mean they are recalling a childhood sexual assault. A sexual assault in aged care can also trigger memories of earlier trauma. You need to listen and you need to provide support.

Please imagine you are in the situation of having been sexually assaulted, you have the feelings of it, but can't communicate those feelings, or relate them to any event as the memory is gone. You still feel the distress but can't say what it relates to.

Understand what the resident is feeling and act to make sure they feel safe and are not distressed. Understand that there may be triggers, for example if the victim still has contact with another resident or staff who has sexually assaulted them. Please consider changing at least something in their room space or care, by way of acknowledgement, and to signal to the victim that they have been heard and are being actively protected.

Give the victim the option to access a sexual assault counsellor – they don't have to be able to speak to benefit from someone who can provide them with professional support.

This may seem meaningless to you, if you are still in the head space that action is not worthwhile unless the recipient is grateful or responsive, but I'd argue that inside the heart of the person, it will be appreciated.

This paper is about sexual consent – but it has focused on sexuality and intimacy more broadly. If you are going to help people living with dementia navigate sexual consent you need to be confident and comfortable talking about sexual intimacy. We

need you to know that intimacy matters to us – because we are human beings. We want you to know the facts about sexuality and we want you to ask us about what we want. Sexual consent isn't a tick box. Its about understanding our human right to sexual intimacy – and understanding that we all need to have the conversations, even when they are not comfortable. We need you to help make sure we are safe, and that others are safe from us.