READY TO LISTEN

In Sickness and Health

A resource for **service providers** working with care partners of people living with dementia

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OPAN Older Persons Advocacy Network

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OLDER WOMEN'S NETWORK OWN NEW SOUTH WALES

DEMENTIA ALLIANCE INTERNATIONAL The global voice of dementia

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The team

This resource was developed for the #ReadyToListen project by a group of people living with dementia and their care partners who are committed to preventing sexual assault of people living with dementia and supporting care partners experiencing unwanted sexual contact, including: Kate Swaffer (Chair); Theresa Flavin; Lynette Roger; Steve Grady; Dubghlas Taylor; Eileen Taylor; and Donna Lee.

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More information

More free resources on #ReadyToListen can be found here: https://opan.org.au/support/support-for-professionals/ready-to-listen

I made a commitment to care for my partner in sickness and health; and that commitment means a lot to me. He needs me more since he got dementia. But he has become sexually demanding, and that's not like him. He would be mortified if he knew what he was doing. I know it's the dementia doing that; but what can I do to stop it? I want to keep caring for him at home – but I need that part to stop.

Thanks, Betty

Introduction

The statement shown above is a compilation of issues for care partners of people living with dementia who experience unwanted sexual demands. It has been taken from research on sexual assault of older women in Australia. The statement illustrates critical issues that are explored in this resource - alongside practical strategies for supporting Betty and other care partners. **Betty is a pseudonym representing a compilation of experiences of people with lived experience.*

Dementia can bring changes to intimate relationships that the person living with dementia may or may not aware of. For example, people living with dementia may say or do things that are out of character, such as becoming:

- less interested in sex
- overly interested in sex (hypersexuality)
- sexually disinhibited (more open) or inappropriate.

Dementia can also affect sexual consent. A person living with dementia may no longer understand the importance of checking sexual consent. Additionally, some care partners may need to work harder to check the person living with dementia understands and provides them with consent for every sexual activity or any other type of intimacy.

Changes in sexual interest and sexual consent for people living with dementia and their care partners isn't something we have talked about much in the past. This may be because care partners feel ashamed or disloyal talking about intimacy issues.

There is no shame in having a disease that changes the way sexuality, affection and intimacy are or are not expressed.

It is also not disloyal to talk about these changes. Talking about intimacy issues to someone who can provide support can be an essential step in making sure care partners have the support they need for their own wellbeing. It is also an important step in a care partner getting the support they need to keep caring for someone at home, if that's their preference.

Not talking about this issue is part of the problem. We need to open up conversations about unwanted sexual demands and sexual assault so we can support care partners. Our motivation for promoting change also reflects the needs of the people living with dementia who are unaware they are placing unwanted sexual demands on someone they care about. As John Quinn stated in the #ReadyToListen Dementia MAP[1]

> *Sexual assault is not a normal part of dementia. I would never do that. But if my brain changed and I lost insight and that happened – I would want to be stopped. If I transgressed a sexual boundary, if I touched someone without consent, that's not okay. There is harm to the other person. There is also a dignity issue for me.*

John refers to the United Nations Convention on the Rights of People with Disabilities[2] and suggests that not taking action to stop a person living with dementia from sexually assaulting another person is also a violation of their right to dignity and respect.

Creating change requires opening up conversations – so that practical strategies and supports can be provided to care partners.

This resource aims to help open up conversations. It has been developed by people living with dementia and their care partners to help service providers understand this issue and better support care partners of people living with dementia who are experiencing unwanted intimacy, sexual demands or sexual assault. The resource was produced for the #ReadyToListen project.

The #ReadyToListen project

The #ReadyToListen project[3] was led by the Older Person's Advocacy Network (OPAN), in partnership with Celebrate Ageing Ltd and Older Women's Network NSW. The aim of the project was to prevent sexual assault in residential aged care. The project was launched in 2021 and was funded by the Australian Government Department of Health.

In 2022, the #ReadyToListen project established a Sexual Assault and Dementia Special Interest Group (SAD-SIG) in collaboration with Dementia Alliance International (DAI).[4]

DAI is a registered charity and international organisation that represents the more than 57 million people living with dementia globally,[5] provides advocacy and support, and educates people living with dementia, and the wider dementia community.

The SAD-SIG draws on the expertise of nine people living with dementia, and one care partner, to help prevent sexual assault and increase the efficacy of the #ReadyToListen project.

[1] https://media.accessiblecms.com.au/uploads/opan/2023/02/RTL2023_DementiaMAP.pdf
[2] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
[3] https://opan.org.au/support/support-for-professionals/ready-to-listen/
[4] https://dementiaallianceinternational.org/
[5] https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00249-8/fulltext

In 2023 the SAD-SIG initiated the *In Sickness and Health* resources to support care partners of people living with dementia who were experiencing unwanted intimacy, sexual demands or sexual assault by the person living with dementia.

About this resource

This resource has been developed for service providers supporting people living with dementia and their care partners. The aim is to promote support of care partners experiencing unwanted intimacy, sexual demands or sexual assault – to promote their health and wellbeing and to assist them to continue their caring role if they wish to.

It includes outlining some of the problems contributing to unwanted sexual contact, namely brain changes and social expectations.

It then outlines strategies for service providers to open up conversations with care partners and information about services they can access.

Factors contributing to unwanted sexual contact

There are many factors that may contribute to unwanted sexual contact, in this section we outline two - brain changes and social expectations.

Brain changes

Sexuality is a normal function of human beings and individuals have their own sex drive that is typical for them. People living with dementia are still sexual beings,[6] with sexual rights and responsibilities[7] and the need for information and support related to their sexual expression.

Brain changes related to dementia may lead to unwanted intimacy, sexual demands and sexual assault. People living with dementia may no longer know when, how or where to appropriately express sexual desire.[8]

Brain changes can result in sexual disinhibition,[9] hypersexuality[10] and unwanted sexual contact,[11] including sexual assault.[12] Dementia may also affect a person's ability to moderate their sex drive.[13]

It may be helpful for care partners to understand that sexual changes may be due to the disease – and the person living with dementia may have little or no control over these changes.

[6] https://www.opalinstitute.org/rights.html
[7] https://media.accessiblecms.com.au/uploads/opan/2023/02/RTL2023_Charter.pdf
[8] https://www.dementia.org.au/support-and-services/families-and-friends/personal-care/intimacy-and-sexual-issues
[9] https://baycrest.echoontario.ca/wp-content/uploads/2019/01/7-Resource.pdf
[10] https://www.cambridge.org/core/journals/advances-in-psychiatric-treatment/article/hypersexuality-in-dementia/E2CFB1E9F2791BBCAE15F9580388BD19
[11] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3596201/
[12] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf
[13] https://www.dementia.org.au/about-us/news-and-stories/stories/does-dementia-impact-your-libido

Social expectations and shame

Challenges relating to unwanted intimacy, sexual demands and sexual assault by people living with dementia are talked about in residential aged care – because they are witnessed by service providers. However, the focus is seldom on the experiences of people living with dementia and their care partners who are living at home. Previous research[14] has identified the following examples, shared by service providers:

> *'…carer was highly stressed by the constant demands of her husband for sex. He had always wanted sex often and the desire remained, but the ability did not. His repetitive pattern of demand was a constant, but not the only source of stress. He was not amenable to change because of his significant memory loss and did not know how much he was demanding. The impact on his wife was as if she was being abused even though it was unintentional, i.e., related to forgetfulness, a repetitive refrain for sexual contact.*
>
> *The best way we could assist was to listen to her distress, be empathic, suggest possible strategies to try to protect herself with not much success and take him out of the home to ensure she had regular breaks. She did not want to relinquish care. His demands lessened in time. It was only when he was placed [in residential aged care] some years later that her constant digestive symptoms and pain lessened. I have no doubt that the stress she was under contributed to her health problems.'* (Survey 27: aged care service provider)
>
> *'[An older woman] was basically … raped, if not nightly, almost, by her husband who had Alzheimer's, and he had previously also been a very loving partner, and she knew that he was confused … and she knew that he… wasn't in control of what he was doing, but it was enormously stressful for her and she was deeply, deeply humiliated by the circumstances and also was fearful about what would happen to him if she told anyone.*' (Interviewee S32: advocacy service)
>
> *'We were working with a woman who was being repeatedly raped by her husband and there were three sons and she was trying to tell them without saying the sexual violence part, she was trying to tell them about what was happening to her, and that she didn't … really want to stay in the home anymore because she just couldn't manage it, she was … in her 80s and really quite frail. Now the sons didn't want to hear about it and I mean in the end she was saying to them, "He wants sex all the time," and they were, "Well what's the problem with that?" … and then kind of joking about the father's prowess at that age, … And the reality is that the three sons and the husband were tied up in the property that they worked on, but two of the sons actually still lived at home…the males were all drinkers, and that was behaviour that had gone on for a very long time.*
>
> *So clearly her first disclosure was to the sons and they were not empathetic and discounted and downplayed her fears and concerns. She was quiet for*

[14] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf

probably another year after that, until the husband, who had dementia but was being prescribed Viagra, ended up with a case worker. The woman built some trust with this case worker and told her what was going on. Then she got an empathetic response.

And the way in which they were able to handle that was to involve the doctor and look at the unintended outcomes of [her husband] continuing to have Viagra, and also by getting him regular respite …, eventually he went into care because of his dementia – the behavioural components weren't manageable at home – and the woman was able to carve out a bit of a safe life for herself at the home (Interviewee S9: sexual assault service).'

Across the narratives there was a recurrent theme of care partners complying with unwanted sexual demands because they didn't know what else to do. As one aged care service provider noted:

'... what is really tragic … is many of these people … are seeing this almost as therapeutic; that is, not for them, but what they're saying is that a lot of carers, especially where their partner is demented, that they're using sex as a means of calming the person down and to appease behavioural issues.

So, what … these people were telling me was that their partner, who obviously they once loved and once had a very good sexual relationship with, as part of their dementia process have become dis-inhibited or hyper-sexual and wanting to have sex with them. And these women are … actually agreeing to it because it's the quickest pathway to quieten the person down.' (S33: aged care service provider)

Over hundreds of years, marital rape immunity laws have established a sexual power imbalance in heterosexual relationships – husbands were not required to negotiate sexual consent with their wives and were immune from rape prosecution.[15] A cultural tone was set and women who challenged this dynamic were labelled vindictive.[16]

Marital rape immunity laws were reformed in the 1980s in Australia[17] but the legacies of these laws continue. Older women in heterosexual relationships were expected to provide for the male partner's sexual needs[18] and this can be a significant barrier to older women reaching out for support when they experience unwanted sexual demands.

Unwanted sexual demands may be experienced by care partners of all genders. The male partners of women with hypersexuality may find their concerns are not taken seriously by service providers who cannot understand why a man would not want a woman who was constantly demanding sex. Additionally, research has not yet documented the issues in same sex relationships or for Trans and Gender Diverse people.

[15] https://law.unimelb.edu.au/__data/assets/pdf_file/0004/1699006/37_3_7.pdf
[16] http://www.auswhn.org.au/blog/marital-rape/
[17] https://www.alrc.gov.au/publication/family-violence-a-national-legal-response-alrc-report-114/24-sexual-assault-and-family-violence-2/history-of-activism-and-legal-change/
[18] https://www.routledge.com/Addressing-the-Sexual-Rights-of-Older-People-Theory-Policy-and-Practice/Barrett-Hinchliff/p/book/9781138189188

Understanding that brain changes can change the way a person living with dementia expresses their sexuality is important. It provides an imperative for service providers to check what care partners are experiencing and give them information about strategies for support.

Similarly, understanding the social expectations and shame related to sexual demands and sexual assault provides an insights the difficulties for care partners in disclosing these issues.

Lack of disclosure by care partners is not an indication that this issue is rare. Rather it is an indication we have not yet created safe spaces for care partners to disclose unwanted sexual demands and sexual assault and seek the support they need.

Strategies for service providers

This section outlines strategies for opening up conversations with care partners about their support choices.

Carer autonomy

1. Care partners may fear that disclosing their experiences will mean separation from the person they are caring for. Provide reassurance this will not occur and information about any circumstances which would require reporting (and to whom)
2. Give reassurance about the approach you will be taking i.e.: providing information to the care partner about their options
3. Let the care partner know how the information they disclose will be used e.g.: with whom it will be shared.

Being #ReadyToListen

1. Find out about the services the care partner can access (read the list on the following page and be familiar with these services)
2. Understand that ‘support’ involves practical strategies in addition to listening
3. Give the care partner permission to speak about their experiences (see below)
4. Let the care partner know your conversation is in confidence (if it is)
5. Ask the care partner what they want to see happen
6. Offer to get more information for the care partner, if needed
7. Assist the care partner to contact the relevant services, if needed
8. Let the care partner know you are listening without judgement.

Giving Permission to Speak

1. Check the care partner has privacy to disclose if they wish (e.g.: without others hearing)
2. Let the care partner know that you are aware that sometimes unwanted sexual demands happen and that there is support available e.g.

    - *Do you mind me asking if things have changed in your intimate relationship?*
    - *I know that sometimes care partners experience sexual demands from a person living with dementia. Do you mind me asking if that is something that is happening to you?*
    - *If you like I can tell you about some of the things we can do to support you, or maybe you can tell me how I can help?*

3. Ask the care partner what they would like you to do e.g.: contact their GP to organise an assessment, or Dementia Support Australia hotline for advice, or organise respite care for the person living with dementia etc
4. You don't have to have all the answers immediately – let the care partner know you will find out more information and get back to them
5. Check repeatedly that what you are doing is okay – let them know where this information will be recorded and who will have access to it (they may want privacy)
6. Follow up - check in to see how strategies have worked for the care partner.

Accessing specialist advice

1. Let the care partner know what specialist services can assist
2. Seek permission from the care partner before making any referrals
3. Offer to contact the specialist services for them – they may feel overwhelmed
4. Follow up on the contact.

Reporting requirements

1. The Serious Incident Response Scheme (SIRS) includes home care and service providers are required to report unwanted sexual contact if it occurs in connection with the provision of care
2. Organisations should have their own policy guidelines, compliant with each state/territory laws, to guide service provider any reporting requirements related to unwanted sexual contact of a care partner.

Useful information

Dementia and carer support services

- **GP Advice Line**: Dementia Support Australia has a GP Advice service. GPs can contact the DSA Medical Specialists for clinical advice and support for people living with dementia who are experiencing behaviour change. The GP Advice Service can be accessed through the website: https://www.dementia.com.au/who-we-help/health-care-professionals/services/gpas

- **Dementia Support Australia:** support people living with dementia and their care network. When a person living with dementia is experiencing changes to their behaviour, DSA can work with you to understand the causes and develop personalised strategies. Dementia Support Australia's helpline is available 24 hrs a day every day of the year 1800 699 799. Or you can reach out at https://www.dementia.com.au/

- **The National Dementia Helpline:** this free telephone support service provides free information and advice 24 hours a day to people living with dementia, care partners and others. Phone: 1800 100 500 or visit: https://www.dementia.org.au/helpline

- **Carer Gateway:** provides access to free carer counselling and other emotional and practical services and support for carers. Call: 1800 422 737 or visit: https://www.carergateway.gov.au/

Other services

- **1800RESPECT**: is the national domestic, family and sexual violence counselling, information and support service. They are available 24 hours a day, 7 days a week. Call 1800 RESPECT (1800 737 732) or visit: https://www.1800respect.org.au/

- **1800FULLSTOP**: confidential counselling for people who have experienced sexual assault and for family members. Call 1800 385 578 any time or check the website: https://fullstop.org.au/

- **The Older Persons Advocacy Network (OPAN):** helps older people understand and exercise their rights, access aged care services and solve aged care problems. Call 1800 700 600 or visit the website: https://opan.org.au

- **Beyond Blue:** provides a free phone service 24 hours a day on 1300 22 4636 or visit: https://www.beyondblue.org.au/

- **Lifeline:** is a free phone service available 24 hours a day on 13 11 14 or visit: https://www.lifeline.org.au/