READY TO LISTEN

# The #ReadyToListen Dementia MAP

## Guidelines for Preventing Sexual Assault of People Living With Dementia in Residential Aged Care

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OPAN Older Persons Advocacy Network

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**The #ReadyToListen project**
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**For more information contact**
More free resources on #ReadyToListen website: https://opan.org.au/ready-to-listen/

# Key definitions

**Guidelines**
The guidelines in this MAP have been developed to support residential aged care service providers improve responses to, and prevent, sexual assault in residential aged care. The guidelines outline how service providers might approach their obligations under the Quality of Care Principles. The guidelines are not legal advice or a compliance guide.

**Quality of Care Principles**
Reference to the Quality of Care Principles refers to the Quality of Care Principles 2014 (Cth)[1] made under section 96-1 of the Aged Care Act 1997.

**Sexual assault**
The definition of sexual assault varies across each state/territory.[2] The #ReadyToListen resources use the term to encompass 'unlawful sexual contact, and inappropriate sexual conduct' as outlined in the Quality of Care Principles 2014 (Cth)[3] as follows:

Unlawful sexual contact, or inappropriate sexual conduct

(4) In paragraph 54-3(2)(b) of the Act, the expression "unlawful sexual contact, or inappropriate sexual conduct, inflicted on the residential care recipient" includes the following:
  (a) if the contact or conduct is inflicted by a person who is a staff member of the approved provider or a person while the person is providing care or services for the provider (such as while volunteering)—the following:
    (i) any conduct or contact of a sexual nature inflicted on the residential care recipient, including (without limitation) sexual assault, an act of indecency and the sharing of an intimate image of the residential care recipient;
    (ii) any touching of the residential care recipient's genital area, anal area or breast in circumstances where this is not necessary to provide care or services to the residential care recipient;
  (b) any non-consensual contact or conduct of a sexual nature, including (without limitation) sexual assault, an act of indecency and the sharing of an intimate image of the residential care recipient;
  (c) engaging in conduct relating to the residential care recipient with the intention of making it easier to procure the residential care recipient to engage in sexual contact or conduct.

(5) However, that expression does not include consensual contact or conduct of a sexual nature between the residential care recipient and a person who is not a staff member of the approved provider, including the following:
  (a) another person who is a residential care recipient of the provider;
  (b) a person who provides care or services for the provider (such as while volunteering) other than while that person is providing that care or services.

[1] https://www.legislation.gov.au/Details/F2021C00887
[2] Ibid.
[3] https://www.legislation.gov.au/Details/F2021C00887

**Ready To Listen**
The term #ReadyToListen refers to aged care service providers knowing the risk of sexual assault, understanding indicators, believing those who disclose, acknowledging impacts, providing support and taking proactive steps to protect residents. Being #ReadyToListen is achieved through organisational policy and education for staff and information for residents and their families on sexual assault.

**Perpetrator**
The term perpetrator refers to the person directly engaged in sexual assault[4], as well as people who may induce or assist others to engage in the sexual assault[5]. The term perpetrator is used to reinforce the serious nature of sexual assault.[6]

**Disclosure**
The word disclosure is used by a number of key services[7,8] in relation to sexual assault, and broadly reflects a process for making something known.

**Victim/survivor**
The term victim may be used to refer to the person who has been sexually assaulted[9], particularly to illustrate that a sexual assault has been committed.[10] The term survivor often refers to a person who is going through or has gone through a recovery process.[11] Some resources refer to victims/survivors in recognition that those impacted have the right to choose how they are referred to.

**Affirmative consent**
Affirmative consent makes it clear that a person does not consent to sexual activity unless they said or did something to communicate consent[12]. The objectives of affirmative consent in residential aged care are to recognise that every resident has a right to choose whether to participate in sexual activity and that consent to a sexual activity must not be presumed. Communication of consent requires more than noting a resident was not obviously distressed or didn't say no to sexual activity. Consent is given through words or actions before and continuously throughout sexual activity.

**Supported decision-making**
Supported decision-making involves a person supporting another person, such as an adult with a cognitive impairment, to make their own decisions. Victoria and Queensland are the only Australian States and Territories that have laws on supported decision-making. Supported decision-making recognises every person's right to have their will and preferences heard.

[4] https://www.police.vic.gov.au/sites/default/files/2019-02/Victoria-Police-Reporting-Guidelines--v12-2_7Mar16_gvr.pdf
[5] Ibid.
[6] https://plan4womenssafety.dss.gov.au/wp-content/uploads/2015/04/glossary-web_national_outcome_standards_for_perpetrator_interventions.pdf
[7] https://www.racgp.org.au/afp/2015/march/disclosures-of-sexual-abuse-what-do-you-do-next
[8] https://aifs.gov.au/publications/responding-young-people-disclosing-sexual-assault
[9] https://www.police.vic.gov.au/sites/default/files/2019-02/Victoria-Police-Reporting-Guidelines--v12-2_7Mar16_gvr.pdf
[10] https://sakitta.org/toolkit/docs/Victim-or-Survivor-Terminology-from-Investigation-Through-Prosecution.pdf
[11] Ibid.
[12] https://www.mondaq.com/australia/crime/1136522/affirmative-sexual-consent-laws-passed-in-new-south-wales

*Being #ReadyToListen is about understanding the risk of sexual assault, knowing the indicators, believing those who disclose, acknowledging impacts, providing support and taking proactive steps to protect residents. Sexual assault in residential aged care is never okay. Being #ReadyToListen is an important step in prevention.*

Mr Craig Gear, CEO Older Persons Advocacy Network (OPAN)

## Introduction

This resource has been developed to help prevent the sexual assault of people living with dementia in residential aged care. We recognise preventing sexual assault in residential aged care requires a robust understanding of dementia and the factors that make people living with dementia vulnerable to sexual assault.

Research shows that most victims/survivors of sexual assault in residential aged care are females living with dementia.[13] We propose that it is not the disease itself that makes people with dementia vulnerable to sexual assault. Rather, it is our attitudes to people living with dementia that makes them vulnerable.

The need to challenge these attitudes was made more apparent following The Aged Care Royal Commission's final report.[14] The Commission estimated there are 50 sexual assaults in residential aged care each week and called this "a disgrace and … source of national shame."

Following the Aged Care Royal Commission, there have been reforms to improve reporting and prevention of sexual assault in residential aged care. Reforms include the 2021 implementation of a Serious Incident Response Scheme (SIRS)[15] in residential aged care, which requires, for the first time, that all sexual assaults are reported. To accompany the SIRS guidelines, the Aged Care Quality and Safety Commission (ACQSC) released a fact sheet on sexual assault in residential aged care,[16] which was updated in 2022.

A further significant reform was Australian Government support for #ReadyToListen, a national project to prevent sexual assault in residential aged care.

## The #ReadyToListen project

In 2021, the first national project to prevent sexual assault in residential aged care was launched. The #ReadyToListen project provides education and information to improve responses to sexual assault disclosure and prevent sexual assault. The

[13] https://pubmed.ncbi.nlm.nih.gov/28402419/
[14] https://agedcare.royalcommission.gov.au/publications/final-report
[15] https://www.agedcarequality.gov.au/consumers/serious-incident-response-scheme#compulsory%20reporting
[16] https://www.agedcarequality.gov.au/sites/default/files/media/sirs-unlawful-sexual-contact-or-inappropriate-sexual-conduct-fact-sheet-june-2021.pdf

project is funded by the Australian Government Department of Health and is delivered by the Older Persons Advocacy Network (OPAN), in partnership with Celebrate Ageing Ltd and the Older Women's Network, New South Wales.

The #ReadyToListen project emphasised the importance of hearing the voices of people living with dementia. This resource was developed in consultation with people living with dementia and co-authored by a person living with dementia – providing valuable insights into strategies for change.

## About this resource

This resource begins with the perspectives of people living with dementia. Kate, Theresa, John and Anna share their concerns and solutions – in their own words. Their insights are powerful reminders of the importance of listening to people with dementia. Their voices represent the start of a process of listening to people with dementia.

We include a section on the human rights of people living with dementia, referencing the UN Charter on the Rights of People with a Disability. We refer to articles or elements of the Charter to highlight the urgent need to prevent sexual assault of people living with dementia and to ensure victims/survivors are supported.

Then we outline evidence related to sexual assault of people living with dementia in residential aged care, using the #ReadyToListen MAP as an umbrella to create a Dementia MAP. The development of the Dementia MAP enabled us to better understand prevention in the context of caring for people living with dementia. In turn, the Dementia MAP helped to refine the content of the more generic MAP Guidelines.

In the final section, a family member shares the story of Sandra, a resident living with dementia who reported she was sexually assaulted in a residential aged care home. Sandra’s story highlights the pressing need to listen to people living with dementia who disclose sexual assault. We reflect on Sandra’s experiences by applying the Dementia MAP to highlight opportunities for prevention.

This resource is part of a suite developed for the #ReadyToListen project. We encourage you to visit the #ReadyToListen webpage to access the other free resources.

# Perspectives of people with dementia

## Sexual assault in residential aged care[17], Kate Swaffer

Over the last 20 plus years, we have had no less than 20 formal reports or inquiries onto the challenges we have been facing in Australia of poor care in residential aged care, to the point where most of these institutions should not have the word ‘care’ in their names.

However, the interim report simply titled ‘Neglect’, and the final report from the Royal Commission into Aged Care Quality and Safety, which followed the two decades of reports or formal enquires, which was the culmination of 28 months of work, and which included more than 10,500 submissions and 23 public hearings involving 641 witnesses, did not address the issue of redress for past or future violence, abuse and neglect in its 124 recommendations.

Every second that you remain silent about sexual assault, or any other form of violence, abuse or neglect in residential aged care, or indeed, of any person, anywhere, you are part of the problem.

## People with dementia have the same rights as all others

People with dementia have the right **not** to be sexually assaulted, and if they are sexually assaulted, they have the right to legal action against the perpetrator. The Aged Care Royal Commission estimated there are 50 sexual assaults in residential aged care every week. And the research is clear that most victim/survivors of sexual assault are women with dementia.

Given that sexual assault is such a significant issue for people with dementia – why has so little been done to prevent it?

I believe the answer to this is very complex. In part it is due to ageism and ageist politicians, health care professionals and aged care service providers, as well as civil society more generally.

It is also due to a lack of education and negative attitudes about, and towards, people with dementia. For example, in the Alzheimer’s Disease International 2021 World Alzheimer’s report[18] on attitudes and stigma found that:

- almost 62% of health care providers worldwide think that dementia is a normal part of ageing
- 40% of the general public think doctors and nurses ignore people with dementia.

[17] https://www.youtube.com/watch?v=XbhL2oYoYmg
[18] https://www.alzint.org/resource/world-alzheimer-report-2021/

That so little has been done to prevent sexual assault is also due to a large percentage of service providers lacking an understanding of dementia. The devaluing of people with dementia causes disrespectful and neglectful care.

## Less than human . . .

When people are diagnosed with dementia, they are stripped of their full citizenship. I know this from my own personal experience. Dementia has taught me many things, especially the sense of otherness that the late Dr Martin Luther King talked about.

People living with dementia are perceived as less than human. We are denied universal health coverage, including rehabilitation, and we are often denied adequate health care for non-dementia related illnesses after diagnosis.

For example, there is a commonly held myth that people with dementia don't feel pain, or that if we do feel pain, we won't remember it. So, we get less pain management than a person without dementia who has the same needs. That's wrong. We are human, we feel pain – even if you can't see it or we can't express it. And we have the right to access appropriate pain management.

Many people with advanced dementia are also denied palliative care.

In a similar way, some service providers think if someone with dementia is sexually assaulted, they won't feel distressed and they won't remember the sexual assault, so it doesn't matter.

This is truly appalling.

## The lack of redress

If the same situation occurred with children in day care, we would take legal action.

In fact, one study[19] showed that in 58% of sexual assaults, staff reported there were no adverse consequences for the resident! Well, it does matter. Sexual assault of all people, including people with dementia matters.

Just because a person with dementia, who has been sexually assaulted, may not be able to tell you about their distress, or cannot remember it and just because you cannot see their distress – that does not mean they are not distressed. Or that legal action should not be taken.

Too often I hear stories of people with the power to act, including police who do not believe persons with dementia. This is wrong.
People with dementia who are sexually assaulted have the right to be recognised as fully human. This includes:

- The right to have the harmful nature of sexual assault recognised, reported on and acted on

[19] https://www.health.gov.au/resources/publications/prevalence-study-for-a-serious-incident-response-scheme-sirs

- The right to access support services
- The right to be safe from further sexual assault.

Everyone has a role to play in preventing sexual assault of people with dementia. And it begins with challenging the myth of sexual assault as being less harmful for people with dementia. Residential aged care service providers need to understand this. Additionally, our governments and advocates, and particularly our dementia-specific services, need to understand it.

Whilst doing really amazing work, younger advocates for sexual assault are not talking about, or advocating for, prevention of the sexual assault of older people. To be frank, I see this as part of the problem, which may also be due to ageism.

In advocating for the rights of any cohort not to be sexually assaulted or violated in any way, then let us not forget older people.

I will hopefully have the privilege of getting old one day, too. I would want to know whether I will be safe from all forms of violence and abuse and that my rights will be upheld.

It is our attitudes that make people with dementia vulnerable.

And if you do not understand this – you are part of the problem.

## Being lost and finding our own way, Theresa Flavin

*My number one message to aged care service providers is use your eyes as well as your ears . . . then you will see signs of sexual assault. Sexual assault happens, it's not okay to just hope that it won't. Hope is not enough.*
*We need service providers . . . to understand that it is not ok to say, "Oh, granny doesn't say no, so she must mean, yes, that's all fine."*

That's how it's always been in the past and it's not ok. We need to move away from that. And that will happen when we get some leadership.

Before I had dementia, I remember what life was like. I remember the feeling of being part of the community and just taking for granted that I went to work every day and I supported the family and I had autonomy and was in charge of my life. I remember that, but it's almost like an abstract concept now to me. I just took it so much for granted, that I was in charge, and I had the freedom to make my own choices.

So, for me, the diagnosis and the living with dementia, the hardest part was having to step back from that autonomy for multiple reasons: for safety, for risks, to make sure jobs were done properly. And the feeling of accomplishment that you take for granted from your work and your family is not there anymore. And you have to sort of almost give yourself permission to change your life and change yourself.

I think I've described it before, it's like a divorce. You are divorcing the life that you had before. You're divorcing the future you thought you had. And it takes a few years to grieve that. And you almost have to grow into a whole new person with a whole new life and a whole new future and have to get acceptance of that.

When you're able to do that, you can change things so that you can live better for the time you've got. And it's possible. It's not an easy process. I think I was fortunate that I pressed so hard for a diagnosis when I was younger and didn't allow myself to get fobbed off with the 'menopausal disappointed middle-aged lady' thing that most people seemed to think I had.

### Intimacy and consent

My sexuality is almost like a journey. When you're given a diagnosis of dementia, everybody rushes to tell you to get your affairs in order. And as Kate Swaffer says, it's the prescribed disengagement, where you're told to essentially sit and wait and hand everything that's important in your life over someone else. And intimacy and relationships weren't covered anywhere. You're just left to it.

And there's a reluctance to discuss intimacy and relationships because nobody knows what to say, because there is no information out there. There's no resources or research or tools to help people living with dementia navigate this new landscape that we are living in. So that's something people living with dementia have had to work out for ourselves.

At first, in the earlier stages of dementia, it really didn't have an impact on intimacy. Things were the same. But as dementia has progressed, what I see happening for me personally, is that my memory doesn't work the same as it used to. I'll remember feelings and emotions. I don't remember facts and figures. I've tried to learn to work with what I've got, but the downside of that is you use your senses to ground yourself, to know where you are in time and space. So, if I'm talking to someone and I drifted away into feelings and emotions, I can touch the table and bring myself back to here.

If you're in an intimate situation, without going into too much detail, often your eyes are closed. You're using your senses. You're sort of going with what's inside of you. So even though I'm blessed to be in a committed and safe relationship, you don't have that anchor to the present. I'd almost describe it as like, if you're in deep meditation and you forget to come back. You're just there and then you are not.

I discovered this by accident when we were being intimate, and I got lost. I found myself recalling something that happened a long time ago and I became quite distressed. It was so distressing for both of us because neither of us really knew immediately quite what happened. He didn't know if he'd hurt me or what was going on. It actually took us a couple of weeks to really process what happened. He had to unfortunately wait for me to work out very slowly, what was happening in that moment.

It was also something that was really hard to come back to him with and to explain. And in the best of circumstances, with a beautiful man that I trust, and I had to go to him and more or less tell him about trauma that I thought I had packed away years and years ago. And something good came out of that because it made us really aware of the fact that this is one more thing that we can't take for granted anymore.

We didn't grow up in an age of consent. It's not like the beautiful affirmative consent that we have now in our country. We grew up in an era when, if you didn't say no, it meant yes. And thankfully, now, we're aware that there is a better way. We decided as a couple never to take consent for granted anymore, not only as a matter of respect for each other, which I wish we'd always done, but also because it's the best way to approach these things.

But when you have one partner that's vulnerable like this, in terms of being able to stay in the moment, what we realized was that we have to check in at all times, and ask: are you with me? Are you here?

My husband has got to know how it needs to work, because from his perspective, how he explained it was: he didn't want to be intimate with someone who wasn't intimate back. It's got to be a mutual transaction, as it were. He just can't fathom how

anyone could be intimate with their wife or partner without knowing that they were there in that time, in that space with them.

So even if I was absent, not anywhere in the void, he doesn't feel that that is right or just, or ethical in any way. It's really not right. It's not mutual. So, we were able to develop a way through this by saying we're going to constantly, every couple of minutes, check in, touch, talk, whatever it is. We can't just go and be like 19-year-olds. We just have to do things very differently.

And that's working. But I have to say it was so traumatic and shocking to me that I could get lost like that. I didn't think that was part of dementia. I thought you slowly faded away to nothing. And I learned that you don't actually fade away to nothing. You fade away to everything. And it's like throwing the dice. You can't necessarily choose where you land in this internal landscape.

And unless you've got someone, or support to keep you tethered, it's very easy to get lost. What I'd also say is without clear and genuine support, almost like a scaffold to hold me here, it's more difficult to come back to here. We are finding our way. I am fortunate my husband is able to help keep me in the moment. He didn't roughly jolt me back. He is able to help me be present in a way that doesn't cause grief.

## Supported decision-making and sexual consent

This brings me to the people who don't have the luxury of a trusted partner, where they don't necessarily have the knowledge or the understanding of how to support a partner with dementia in these intimate situations. That frightens me and troubles me of just how distressing this can be for someone who isn't necessarily able to articulate what's the matter, or even to articulate that there's anything the matter.

A disability like dementia means we can't communicate the way the outside world expects us to, or wants us to, but it doesn't mean we're not communicating. It means you're not listening. If I couldn't speak, I could still communicate. We all know that. But no one's looking. No one is listening.

The fact that there is no support for families in this area is appalling. This to me is the number one area that any person living with dementia wants to know. Our families and staff need to be educated about ongoing and positive consent. It's not enough to check that someone hasn't said 'no'. It's about knowing what we are doing, knowing who we are doing that with, knowing this makes us happy and giving our agreement freely. This applies to intimacy – and it applies to the rest of our lives. It's a basic human right.

The fact that families are out there across the world, knowing that this is happening with their parents or in their families, and they're just desperately hoping it goes away. And that's the best they can do because there's nowhere to reach for information on how to navigate this. There's no one to teach us. And that makes me desperately upset because the only time it goes away is when a person with dementia falls silent. And when you're silent, that really is very, very hard to come back from.

When I raise the subject of sexual consent, people are so uncomfortable, it's so taboo to discuss sexuality, particularly with older people. No one will touch it. No one will touch it within their families. No one will touch it in residential care. Care workers don't approach a family member and say, "Hey, your dad is bothering your mom a lot. Or your mom is bothering your dad, or your dad is bothering your dad." We're so afraid of upsetting people, but what about the people who are being upset? What about the people with dementia? We have a duty to stand up for them.

If a person cannot provide affirmative consent to anything, it shouldn't be done. My position and my husband's position is that if you can't say, 'yes, I'd love to', it's not going to happen. It's very black and white for us. I believe everyone should have that right as a human being. That if you don't say yes, it doesn't happen. And that is all. I don't think there's really any more to discuss.

## Impacts of sexual assault

I have heard that staff in residential aged care don't believe that sexual assault of people with dementia causes harm. To be perfectly honest, that makes me just want to go and throw up. It's like, fuck off! Pardon my French, but fuck off! No impact!!! I'll tell you very, very clearly, there is most certainly impact. There most definitely is impact. That's appalling to me that staff would think there is no harm. There is always harm. Always, always harm. And to assume that there isn't just because the person who was sexually assaulted has dementia or can't tell you, is appalling. There's always, always harm.

Any service provider who makes that assessment that there isn't harm, they should step into the shoes of the person with dementia. Take a week in that residential care facility and spend some time to see how they like it. It's so unspeakable that anyone would ever even consider that there is no harm from sexual assault. Is there harm to a child who is sexually assaulted? No one says there's no harm to a child who is sexually assaulted when a child doesn't speak up about the sexual assault. Why would an older person or a person with dementia be any different?

Residential aged care service providers need to take action to protect people with dementia from sexual assault. But they don't. There is this passive hope; they desperately hope that this will go away. It only goes away when the person dies.

## Zero tolerance and reporting

Sexual assault of people with dementia in residential aged care should be reported to the Aged Care Quality and Safety Commission's Serious Incident Response Scheme and the Police. Absolutely. It's still a crime. It's still morally, ethically, and culturally wrong. And even if it weren't criminal, it should not be allowed. Surely, we are vulnerable and need some sort of protection.

If it was a perfect world, if you were entering residential care, the service would have a zero-tolerance policy on sexual assault, and that would be made very clear everywhere in the building, on their materials – that they have a zero-tolerance policy on sexual assault. They would tell staff that if they see any evidence of anything

untoward going on, that it must be stopped and that services will be called to support the person with dementia.

A person with dementia who reports sexual assault may remember a historical experience, and they may also currently be being sexually assaulted. The current sexual assault may trigger memories of the past sexual assault as well. They may be distressed at both – simultaneously, because you go back and forward in time. The fact that we have an impairment doesn't mean sexual assault should not be investigated. And the fact that we have been sexually assaulted in the past does not mean it isn't also happening now.

We need residential aged care services to lead from the top, to step up, get some leadership and really put it out there that they have a zero tolerance for any sort of sexual assault. Any type of sexual assault will be taken seriously and followed up.

People with dementia have the right to be believed when they report sexual assault. When they are telling the story about what happened, they may be anxious, they may be frightened, they may get mixed up. They may tell bits of this, some bits of that. To the outside world, the story might not sound good – it might not sound believable. The anxiety and dementia may mean the story gets mixed up. But that doesn't mean they weren't sexually assaulted. That doesn't mean they should not be heard. People with dementia have the right to be believed and protected from sexual assault.

People with dementia have the right to be believed. Is there a difference in the way we would approach a 12-year-old who has been sexually assaulted and is frighted and anxious? Why are we not afforded the same courtesy or the same rights for sexual assault to be properly investigated when we report it?

My number one message to aged care service providers is use your eyes as well as your ears to identify signs; then you will see signs of sexual assault. Sexual assault happens, it's not okay to just hope that it won't. Hope is not enough. We need service providers on board. We need them to understand that it is not ok to say, "Oh, granny doesn't say no, so she must mean, yes, that's all fine." That's how it's always been in the past and it's not ok. We need to move away from that. And that will happen when we get some leadership.

## The role of dementia services

There is a lot of things that dementia services could do. Probably too many to count. But the first thing I would urge them to do is to get a backbone and call this out. At the minute, I have looked and I have looked, and I see acknowledgement that this is a problem but no solution, no resources, no links, no nothing. Dead end. That's all I see.

So, number one, I would ask that these institutions, who are well funded, that they take a step outside of their own personal comfort zone and take a step into our world and actually put some resources out there telling us what the hell can we do if this is going on. They need to tell us who we can talk to. They need to teach us how to implement supported decision-making about intimacy into our family lives.

This is the most basic thing that these big organizations can do. They can step up and really highlight that this is the number one issue for people with dementia who are in intimate relationships. It's much more important than what happens to our money or what kind of healthcare we get.

When you've got dementia, your priorities change so much. The only thing you have really is your body. Everything else is more or less unimportant. We've just got this, our bodies. So for me, my emotions are how I relate to memories and to the worries. And when someone impacts on those, it's really detrimental.

So, what I'm asking is: please step up. Take up this issue the way the #MeToo movement has done for the younger ladies. How about we get a little bit of that and get some structured assistance? We need someone we can call who isn't going to give us links down the phone. If I call the helpline they dictate internet links over the phone, which I can't remember. They really need to step out of this self-service mode and move into a holistic approach, training us for life with dementia.

We need an intensive day of education about what supported decision-making is, what it looks like for sexual consent. We all want to do the best we can, but we've got no tools. We've got no resources. And who's sitting around in their home thinking, "I must Google supported decision-making." This self-service model that we currently have, where everyone has to reach for their own assistance through the internet, it's not very helpful when you don't already have a base of knowledge to know what to look for. So, I think we need a bit more proactive support coming through to people living with dementia.

My key message to dementia services is grow up and grow a pair, step up and get some leadership in this arena because we've got nothing. People in Australia have nothing. We have no tools, we have no information, we've got nothing and we're vulnerable. And it hurts and it's painful and it's depressing.

And at the very, very least, enduring sexual assault has a negative effect on your trajectory because the more depressed you are, the more you withdraw, the less you have in this world; and the less reason you have to come back to this world. You stay in your safe space. And surely, that's inhuman. It should be the number one priority for dementia and aged care services, as far as I'm concerned. There needs to be education on how to support families with dementia in intimacy, we need support with decision making.

Once I started talking about sexual consent with other advocates and care staff and medical professionals, the stories were just … it was overwhelming. It was like someone was rolling a big rock down a mountain. It was almost more traumatizing than my own experience, listening to what's going on and the magnitude. That made me think, what can I do? And the most powerful thing I thought was to share what happened to me, because that's what is missing in all of this. People are talking for us and about us, but there's nobody stepping up and saying, "Oh, I had this experience."

I'm just lucky that I was able to make something good out of it. I'm in a safe place to talk about this. The people with dementia who aren't in a safe place, we won't get them to talk. Somebody's got to say something different.

I’m sharing my personal perspective in the hope that service providers will have a deeper understanding that people living with dementia, regardless of their ability to communicate, are conscious and aware human beings. We are vulnerable to pain and fear, and it’s my sincere hope that if you are in our lives supporting us, that you will step out of your comfort zone and help ensure that any acts of intimacy are made with full consent. If that is unclear to you, please help us to either choose, or decline safely. We depend on you.

## Out of character, John Quinn

*Age care service providers shouldn't fob sexual assault off as a normal part of dementia. If a resident with dementia is touching another resident who doesn't consent, he needs to be redirected. If you don't stop him, it's not fair on the female resident; it's also not fair on him.*

*There are boundaries, if people with dementia can't see the boundaries you need to show them where the boundaries are. Redirect, divert, not the pharmacological option.*

*This scenario is a bit prickly for me to discuss. I couldn't imagine it. I would want staff to take steps to stop me. I would want staff to understand that my brain may have changed, and I may have lost insight – and 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 resident. There is also a dignity issue for me.*

As a male with dementia, I would be mortified if I ended up in residential aged care and was sexually assaulting another resident because I didn't know what I was doing. Aged care service providers need to better manage men with dementia who sexually assault women in residential aged care – because it's not fair on the poor woman who is sexually assaulted and it's also not fair on me. I would never do that. Ever.

My view may not reflect the view of all males. I know that. But through my lifetime I have been very respectful of women. I have never struck a woman; never even contemplated it. I would never sexually assault a woman. I dare say there are men out there that have different views and exhibit different behaviours – but I never have, never would.

If I was in residential aged care and my dementia progressed and I didn't know what I was doing and I ended up sexually assaulting another resident, I would be mortified. I would want some sort of intervention to take place. I would want someone to articulate to me my errant behaviour. I would want someone to tell me it's not appropriate. I would want someone to tell me the other resident has not consented and that there are sexual boundaries that I am crossing. I would want to be stopped.

If I was doing that and the staff didn't stop me, then they are negligent in my view. If they didn't stop me then they are condoning that behaviour. They can't excuse that behaviour because the person has dementia. A person who is sexually touching another person without consent needs to be stopped.

Some people with dementia need help to remember where the boundaries are. When I go into residential aged care I expect to be checked if I do something that is wrong. I wouldn't be affronted. I would want to be stopped. I have the right to be told that what I am doing is wrong. I have the right to be redirected. The staff need to understand that that is something I would never do and if I can't remember, then they need to remind me.

I would need residential aged care service providers to understand that sexually assaulting another resident is not in character for me. They need to stop me to make sure that the female resident is safe. They also need to stop me because that is undignified and disrespectful of my rights to maintain my values as well.

I think staff in residential aged care are ageist if they don't stop residents sexually assaulting other residents. Ageism is worse for people who have dementia. Some people believe our value to the community diminishes; they think we can no longer contribute – and that we are no longer of value.

The staff shouldn't fob sexual assault off as a normal part of dementia. If someone has lost their inhibitions, he may think another resident is his wife and he may have lost the ability to negotiate sexual consent. There may be no malice on his part, but he has the right to be made aware that what he is doing is not appropriate.

Staff redirect residents when they get lost or make a disruption that impacts on someone else's life; they need to do that with sexual assault as well. If a resident with dementia is touching another resident who doesn't consent, he needs to be redirected. If you don't stop him, it's not fair on the female resident; it's also not fair on him. There are boundaries, if people with dementia can't see the boundaries you need to show them where the boundaries are. Redirect, divert, not the pharmacological option.

This scenario is a bit prickly for me to discuss. I couldn't imagine it. I would want staff to take steps to stop me. I would want staff to understand that my brain may have changed, and I may have lost insight – and 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 resident. There is also a dignity issue for me. I would be ashamed that I did that.

Some staff in aged care have become so desensitised that they are immune to the disrespect and the indignity, they turn a blind eye. They are not affording the residents dignity and respect. A person with dementia doesn't have the right to sexually assault another person. We all deserve dignity and respect and to ignore the right to consent is not respectful and it does not recognise our dignity and humanity.

Too often assumptions are made that sexual assault is a normal part of dementia and that nothing can be done. Neither of these are true. Staff in aged care have to make sure that we know what we are doing and that we are not crossing sexual boundaries. I don't want to cause harm to anyone and if I don't know what I am doing and I am causing harm I want to be stopped. Stopping sexual assault is important to stop the harm to the victim, it respects their dignity and humanity. Stopping sexual assault would also recognise my dignity, that this is something that is so out of character and also needs to be stopped to respect my dignity.

A lot of people don't realise that the rights of people with dementia are now recognised under the United Nations Convention on the Rights of People with Disabilities.[20] Article 3 of the Convention talks about the rights of people with dementia to be treated with dignity and respect. If a person with dementia is assaulted sexually in residential aged care, it is a violation of their dignity and respect. If the staff were aware of it and do nothing, they are violating Article 3 of the Convention on the Rights of People with Disabilities.

Article 15 of the Convention talks about the right of persons with dementia to be free from torture or cruel or inhuman or degrading treatment or punishment. Sexual assault is degrading treatment. Its inhuman.

Residential aged care service providers need to understand the Convention. It should be mandatory. This is basic human rights. It's not okay to be bullied or coerced in the workplace or at home, it should not be condoned in residential aged care. Dignity and respect are the bottom line.

Australia along with 100+ countries is a signatory to this Convention. It's not well known that Australia is a signatory. The implications are that service providers should be aware in their care of people with dementia. Also, the Aged Care Quality and Safety Commission should review compliance with Article 3 and 15 in their audits. They need to audit the outcomes of complaints about sexual assault and also check to see that service providers have strategies to prevent sexual assault of people with dementia.

Sexual assault might not be as obvious as the problems with the meals they see on the plates, but it is a critical issue in ensuring that people with dementia are safe and are cared for in ways that promote dignity and respect.

[20] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

## Keep an eye out, protect everyone, Anna

*I think sexual assault affects people with dementia. If they don't want sex, it's sexual assault, it's rape. They might not be able to describe what it is that is happening to them. They are very vulnerable. They are frail and might not be able to stop something that feels wrong, even if they can't articulate that it's wrong.*

*How are people who are non-verbal able to say what's happening to them, other than acting out? Staff have to be aware. A resident might not be able to say: I have been sexually assaulted. So, staff need to know the signs.*

*It's a dilemma when someone has lost capacity to understand what they are doing and to understand that what they are doing is legally and morally wrong. It's hard because they don't have the ability to make that decision; but you got to protect everyone else.*

I have dementia and I know that sexual assault in nursing homes is an issue. It is something I think about and something I have seen.

My friend's father had dementia that affected his frontal lobe and because of that he could no longer understand what other people were experiencing or feeling. Not everyone that has frontal lobe dementia has sexual problems. But he did, with this wife. He didn't understand that it was rape. That happens. They were married for a long time, and he was probably in his sixties or seventies when he got dementia. In the last five years of his life, he got dementia.

A small portion of people with frontotemporal dementia become over sexualised. They want sex all the time even if their partner doesn't. They lose their empathy factor. They don't understand that their partner doesn't want sex.

It was difficult for my friend's mum to live with him until he moved. She had no control over sex. He decided and then it happened. Suddenly it's a different person she has got. She talked to my friend about it. But it was not something my friend could do anything about.

My friend's parents lived in a little villa. There was no care support, just a call or distress button that if something was going wrong it went to the main office and they could send someone down to help. But she wouldn't call for help if he was being

sexually demanding because it was a private thing. She wouldn't ask for help for that. The staff were there to support her, but she wouldn't speak to them about it. She might have spoken to the doctor but not the care staff. She complained to my friend, but she couldn't do much. In that time a couple didn't talk about that side of their relationship easily. It was a big issue, and you couldn't talk about it.

He then started losing the ability to tell where he was. He would get confused. He would wander. Then they said he can't live in the independent area, he had to be in the nursing home where he was in a more controlled environment. The staff had barriers and supervision.

My friend's dad believed marriage was sacred, so he wasn't going to go for any other woman other than his wife. So, no one else was targeted. It didn't create issues for other women. Just my friend's mum. He remembered her for a long time. In the nursing home he was in a bed in a shared room, and he had the bed rails up – it stopped being an issue for her.

I think staff need to be aware that this can be a potential issue for people with advanced dementia who are physically capable. The staff need to know about it, need to be aware it can happen, and they need to know what to do. They need to know it's not every resident. Not every person with dementia has this problem. But staff need to be aware, so they know how to protect themselves and female residents.

Female residents with dementia might be vulnerable to sexual assault. If you have a ward, you need to have a segregated area so they can be safe. Maybe that would help. You should have the rule that a resident can't go to another resident's room without approval. But staff have to make sure this happens because some people with dementia don't know they are doing that.

I think sexual assault affects people with dementia. If they don't want sex its sexual assault, its rape. They might not be able to describe what it is that is happening to them. They are very vulnerable. They are frail and might not be able to stop something that feels wrong, even if they can't articulate that its wrong.

How are people who are non-verbal able to say what's happening to them, other than acting out? Staff have to be aware. If a female doesn't want to have male staff near her, you have to ask why. You have to look at subtle signs of sexual assault. Staff have to know the people with dementia. They have got to be able to interpret. They can't be told. A resident might not be able to say: I have been sexually assaulted. So, the staff need to know the signs. It's a little bit of Houdini work. They have to be trained enough to see what is going on; to understand when someone is being sexually assaulted.

Staff need to know the residents to know what they are normally like. They can then tell if something is different. You need consistent staff who know the residents. When staff know a resident, they can tell if something is not normal.

Staff need education about how to stop sexual assault. Stopping sexual assault is about knowing the residents and prevention. Don't put a frail female next to a guy

who will cause problems. He might get confused and go to the wrong room and go ahead. Not that he deliberately did, but he might get confused. There is a physical power imbalance. Know the resident. Be aware it could happen. Don't stigmatise everyone. But keep your ear to the ground and be aware it might happen.

If someone is being a bit too friendly put a question mark there. If residents aren't verbal, if they can't talk to staff, they are more vulnerable. So, staff need to put a question there – be on the lookout. Be aware but don't treat everyone like an offender. If you see even a small action heading in the wrong direction, be aware. Make sure female residents with dementia are not in private areas you can't supervise.

Care workers are vulnerable too. Keep an eye out. If you don't feel comfortable get someone else with you, leave the door open and look out for the other staff and residents. It needs to go in the notes and be handed over – so that other staff can be alert that there may be a problem.

Some residents will be lovey and affectionate and they will not sexually attack. You need to be aware. If someone is known to be an offender, they need to be kept away from frail residents and have two staff attending them.

It's a dilemma when someone has lost capacity to understand what they are doing and to understand that what they are doing is legally and morally wrong. It's hard because they don't have the ability to make that decision; but you got to protect everyone else.

## Dementia and human rights

The rights of people with dementia are covered under the United Nations Convention on the Rights of Persons with Disabilities.[21] The Convention provides us with important reminders of the rights of people with dementia to full citizenship, including in the context of sexual assault in residential aged care.

The Convention shifts the perception of people with disabilities as "objects" of charity, medical treatment, and social protection  towards viewing people with disabilities as human beings with rights and who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society.

The Charter includes 50 articles, or requirements. While all articles relate to the sexual assault of people with dementia in residential aged care – the following seven are particularly relevant:

- Article 3(a): Respect for inherent dignity
- Article 12: Equal recognition before the law
- Article 13: Access to justice
- Article 15: Freedom from degrading treatment
- Article 16: Freedom from violence and abuse
- Article 25(d): The same quality of care as others
- Article 25(f): Prevent discriminatory denial of health services

The sexual assault of people with dementia in residential aged care does not respect their right to dignity (Article 3(a)), or their right to be free from degrading treatment (Article 15), violence and abuse (Article 16). People with dementia who report sexual assault are seldom believed by service providers[22] and may not be believed by the police[23] – providing significant barriers to their right to access justice (Article 13).

Furthermore, because victims/survivors of sexual assault who are living with dementia are often not believed[24] they are not given access to same quality of care as other victims/survivors (Article 25(d)) and are denied information about access to health services (Article 25(f) such as sexual assault services.[25]

Our responses to supporting and preventing sexual assault in residential aged care need to be inclusive of people living with dementia. We need to ensure the rights outlined above are promoted and to achieve this we need to understand how our attitudes to people living with dementia are a significant barrier to the promotion of their human rights.

[21] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
[22] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf
[23] See Guidelines for reporting to police at: https://opan.org.au/support/support-for-professionals/ready-to-listen/
[24] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf
[25] See Guidelines contacting sexual assault services at: https://opan.org.au/support/support-for-professionals/ready-to-listen/

## Dementia MAP

The #ReadyToListen MAP provides education and outlines practical strategies to improve responses to sexual assault disclosure and to prevent sexual assault in residential aged care.

Being #ReadyToListen is about understanding the risk of sexual assault, knowing the indicators, believing those who disclose, acknowledging impacts, providing support and taking proactive steps to protect residents.

The #ReadyToListen MAP is underpinned by a belief that residential aged care service providers need to understand the **M**yths, facts **A**nd **P**ractical strategies to be #ReadyToListen when sexual assault is disclosed. The MAP outlines myths, facts and practical strategies for 10 key elements of service improvements.

The Dementia MAP does not replace the #ReadyToListen MAP, rather it sits under it. The Dementia MAP focuses in on the facts of dementia and sexual assault – that relate to people with dementia.

In the section below, facts about sexual assault and dementia are presented for the 10 MAP elements.

### Element 1: Understanding sexual assault definitions and prevalence

- Most sexual assaults are motivated by power and control[26] rather than sexual attraction to a person with dementia
- The Aged Care Royal Commission[27] estimated there are 50 sexual assaults in residential aged care each week – most victims/survivors are women with dementia
- The Aged Care Quality and Safety Commission[28] defines sexual assault (unlawful sexual contact or inappropriate sexual conduct) as: any conduct or contact of a sexual nature inflicted on a resident by a staff member or volunteer; any sexual contact without the resident's consent or against their will; where consent is not possible for other reasons, such as lack of capacity.

### Element 2: Clarifying sexual rights and consent

- All residents have sexual rights and responsibilities; sexual expression is a critical part of human wellbeing, and this does not diminish with dementia
- The Aged Care Quality and Safety Commission's guidelines on sexual assault[29] note the importance of checking whether the resident has capacity to consent to the specific sexual activity at that particular time
- Sexual consent requires free agreement[30] to sexual activity and a person with dementia cannot be said to freely agree if they are fearful, are being threatened

[26] https://www.who.int/violence_injury_prevention/resources/publications/en/guidelines_chap2.pdf
[27] https://agedcare.royalcommission.gov.au/publications/final-report
[28] https://www.agedcarequality.gov.au/sites/default/files/media/sirs-unlawful-sexual-contact-or-inappropriate-sexual-conduct-fact-sheet-june-2021.pdf
[29] Ibid.
[30] https://www.abs.gov.au/ausstats/abs@.nsf/lookup/by%20subject/4510.0~2014~main%20features~sexual%20assault~10

or manipulated or coerced, have mistaken the identity of the person or the nature of the sexual act, are incapable of consenting, or wrongly believe the act is for medical/care purposes.

- The absence of obvious distress is not an indicator that a resident with dementia has consented to sexual activity. The signs of distress may be missed in people with dementia,[31] or attributed to dementia, or a deterioration in the resident's physical condition.

## Element 3: Assessing the indicators of sexual assault

- Dementia and impaired communication prevent the early detection of sexual assault[32]
- The physical indicators of sexual assault can include bruises, pain, skin tears, bleeding, redness, swelling and fractures[33], but these are not always present
- People with dementia may present behaviour cues of distress following sexual assault, rather than verbal disclosures, and these include[34]

    - Behavioural markers:
        - indirect statement ("Don't let that man near me")
        - sudden behavioural change such as withdrawing to foetal position or repeatedly refusing personal care, for example, when the perpetrator is in sight
        - agitated or restless
        - oppositional
        - appears distraught or behaves by slamming doors
        - yelling loudly, getting out of bed, or pacing the floor
    - Numbness or shock: older people lying in foetal position, under their bed, or on the floor, difficult to awake, sleeping for long periods, staring blankly, withdrawn and depressed.
    - Physiological upset: changes in appetite, eating, sleep patterns, and mood levels; uncontrollable crying spells

- Changes in behaviour can also include depression, anxiety, post-traumatic stress, social or emotional withdrawal, crying, sweating, trembling, distress, agitation, anger, violence, absconding, seeking comfort and security, being fearful of others, sleep disturbances, refusing to go to bed, going to bed fully clothed, refusing personal care or requesting a door lock[35]
- Victims/survivors with dementia experience trauma; the suggestion that victims/survivors 'won't be distressed or won't remember' is not an acceptable justification for sexual assault, nor for inaction to prevent sexual assault. Sexual assault is no less serious because the victim/survivor has dementia.[36]

[31] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf
[32] https://www.ojp.gov/pdffiles1/nij/grants/216550.pdf
[33] https://www.agedcarequality.gov.au/sites/default/files/media/sirs-unlawful-sexual-contact-or-inappropriate-sexual-conduct-fact-sheet-june-2021.pdf
[34] https://www.ojp.gov/pdffiles1/nij/grants/216550.pdf
[35] https://www.agedcarequality.gov.au/sites/default/files/media/sirs-unlawful-sexual-contact-or-inappropriate-sexual-conduct-fact-sheet-june-2021.pdf
[36] https://www.ojp.gov/pdffiles1/nij/grants/216550.pdf

## Element 4: Identifying the impacts of sexual assault

- Dementia has no correlation to whether a person is capable of suffering from a traumatic event such as sexual assault[37]
- Sexual assault disempowers and dehumanises victims/survivors, and trauma is not dependent on the 'degree' of sexual assault[38] or whether or not the victim/survivor has a diagnosis of dementia.
- Residents who are sexually assaulted experience high rates of mortality, physical injury and delirium, as well as protracted PTSD[39]
- Fear of perpetrator reoffending may lead to resident distress, insomnia and general failure to thrive[40] in residents with dementia
- People with dementia may have delays in processing and impaired communication which potentially compounds the trauma of sexual assault.[41]

## Element 5: Complying with reporting requirements

- A diagnosis of dementia does not change sexual assault reporting requirements through SIRS[42]
- All sexual assaults are reported as a Priority 1 incident.

## Element 6: Providing immediate safety and support

- Victims/survivors with dementia can benefit significantly from sexual assault counselling and other trauma services
- Victims/survivors who cannot communicate still benefit from reassurances about their safety
- To start by believing[43] victims/survivors with dementia when sexual assault is disclosed is an important part of trauma recovery
- Offering victims/survivors access to an OPAN advocate[44] can assist them to feel supported.

## Element 7: Practicing Open Disclosure

- Open Disclosure is about communicating in ways that promote the safety of the victim/survivor with dementia
- Communicating openly with a victim/survivor with dementia (or their family or surrogate decision maker) should include an apology from the most senior staff as soon as possible
- Dismissing or minimising the impacts of sexual assault on a victim/survivor with dementia dehumanises the person with dementia and is a major barrier to service

[37] https://www.ojp.gov/pdffiles1/nij/grants/216550.pdf
[38] Laura Tarzia: See opalinstitute.org/map for seminar on impacts
[39] https://www.ojp.gov/pdffiles1/nij/grants/216550.pdf
[40] opalinstitute.org/margarita
[41] https://www.nsvrc.org/sites/default/files/Elder_Sexual_Assault_Technical-Assistance-Manual.pdf
[42] https://www.agedcarequality.gov.au/sites/default/files/media/sirs-unlawful-sexual-contact-or-inappropriate-sexual-conduct-fact-sheet-june-2021.pdf
[43] https://www.startbybelieving.org/
[44] https://opan.org.au

providers supporting the victim/survivor and prioritising prevention of further sexual assault.

## Element 8: Providing trauma-informed residential aged care services

- People with dementia who are sexually assaulted experience trauma
- Trauma-informed services support victims/survivors to recover from sexual assault by understanding the impacts of sexual assault on their lives and by ensuring they are believed and heard;[45,46,47] These principles are important for victim/survivors with dementia
- Trauma-informed residential aged care services support victims/survivors living with dementia.

## Element 9: Recognising and reducing resident vulnerability

- Most victims/survivors of sexual assault in residential aged care are female residents with high degrees of frailty, particularly dementia[48]
- Some perpetrators target older women with dementia who cannot call for assistance or are unlikely to be believed if they report sexual assault[49]
- It is our attitudes towards people with dementia that makes them vulnerable to sexual assault, in particular it is
    - The failure to listen to sexual assault disclosures by people with dementia
    - The minimising or dismissal of impacts of sexual assault on people with dementia
    - The lack of education and resources on dementia and sexual assault
- Most perpetrators are male,[50] and this includes residents with dementia and staff.

## Element 10: Protection, prevention and service Improvement

- People living with dementia are at risk of sexual assault in residential aged care; and the risk increases significantly when there is no education or policy to guide staff on preventing sexual assault
- Organisations are expected to have systems and processes that help them identify, assess, and remove risks[51], including the risk of sexual assault for people with dementia
- Residential aged care services need to have systems in place to manage high-impact, high-prevalence risks,[52] including review processes to ensure that risk reduction strategies are effective in preventing sexual assault of people with dementia.

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[45] https://www.anrows.org.au/publication/implementing-trauma-informed-systems-of-care-in-health-settings-the-with-study-state-of-knowledge-paper/
[46] https://www.childabuseroyalcommission.gov.au/sites/default/files/file-list/Research%20Report%20-%20Principles%20of%20trauma-informed%20approaches%20to%20child%20sexual%20abuse%20A%20discussion%20paper%20-%20Treatment%20and%20support%20needs.pdf
[47] https://www.anrows.org.au/publication/womens-input-into-a-trauma-informed-systems-model-of-care-in-health-settings-the-with-study-final-report/
[48] https://pubmed.ncbi.nlm.nih.gov/28402419/
[49] https://www.opalinstitute.org/uploads/1/5/3/9/15399992/researchreport.pdf
[50] https://pubmed.ncbi.nlm.nih.gov/28402419/
[51] https://www.agedcarequality.gov.au/providers/standards/standard-8
[52] Ibid.

## Lived experience – Sandra's story

In this section of the resource, Sandra's story of disclosing sexual assault in a residential aged care home is shared by her family. Sandra's family recall their mother's experiences and how they wish they knew more about sexual assault when their mother disclosed she was sexually assaulted. They note that knowing what they know now about sexual assault would have made it easier to advocate for service providers to listen.

But it's not the responsibility of families to convince service providers to support victims/survivors and prevent sexual assault. Education and resources on sexual assault should be a standard component of the education of aged care service providers. The Dementia MAP aims to assist in achieving that education.

The section begins with Sandra's family sharing her story of reporting sexual assault. Then the Dementia MAP is utilised as a lens for outlining best practice approaches to supporting Sandra and preventing sexual assault.

## What we know now, Sandra's story

When mum reported she had been raped, service providers wrote:

*She must have a urinary tract infection.*
*She has hallucinations of rape.*
*She has rape ideation.*
*She has ideas of being raped.*
*She needs treatment for her behaviour and agitation.*
*Polypharmacy is a significant issue.*
*Her current beliefs about being raped.*
*She has delusions of being raped.*
*She is preoccupied with thoughts of sexual assault.*
*She has rape fantasies.*

*So, we took mum home.*

*I wish I knew then what I know now.*
*I now know that sexual assault happens in residential aged care and most of the victims are people with dementia.*
*If we don't listen to people with dementia who report sexual assault, if we do not believe them – we are part of the problem.*

My mother has always been someone who looked after other people. She was a helper. She loved talking to people and she would stand up for people. She had real principles of social justice; but she wouldn't have called it that. She would just stand up for what was right. She loved to exercise. She would swim a kilometre every day; it was one of her main passions. She taught all her family to swim and a lot of her friends as well. She loved cooking and going to a party with the best food.
Maybe mum's sense of justice was instilled in me. Maybe that is why I stepped out of my comfort zone and shared mum's story. I shared mum's story first for the

#InHerShoes project[53]. And I'm sharing it again here because I want aged care service providers to understand what it is like from the perspective of a person with dementia who has reported sexual assault. I want service providers to understand that when a person with dementia says they have been raped – starting by believing the person with dementia is critical to their safety. It is critical to the safety of all residents, and it is the legal responsibility of service providers.

Not long after mum was admitted to a residential aged care home, she reported that she had been raped. She reported this on multiple occasions over a week and the staff filled out a number of incident reports and called in their nurse practitioner, who then contacted us. We were asked to come into the aged care home for a family meeting.

At the meeting, the facility manager said they wouldn't allocate any male carers to mum unless it was an emergency, because she was clearly agitated around males. They said they would keep the door of her room closed to "*improve her dignity and reduce male contact given current belief.*" The term 'current belief' was their perspective on what had happened – they didn't believe her, that she had been raped. The staff wondered if she has a urinary tract infection and was confused; a dip stick of her urine was all clear.

Despite promising there would be no male staff, male staff continued to provide care and mum became more and more agitated with them, referring to them as rapists. Her agitation got worse, and she was causing disruption to other residents.

The residential manager told us that mum had '*hallucinations of rape*'. They dismissed her rape disclosure as a hallucination. They did not believe her, and we don't know if they properly investigated if she was raped – we were never told that.

When we got copies of her care notes they referred to her 'rape ideation'. That's outrageous. Rape ideation isn't a term anyone uses in response to a rape being reported. To say that my mum had rape ideation – or thoughts and ideas of rape – is dismissive. They were not looking at what mum was experiencing. They did not believe her.

Mum became increasingly agitated, and the staff called in her GP. She had bruising on her arms and staff told us that this was 'self-harm'.

The Dementia Behaviour Management Assessment Service (DBMAS) was contacted by staff to manage mum's agitation. They were not told that mum reported she had been raped.

A Geriatrician referral was made for a review of mum's medications and the Geriatrician noted that mum had been saying she had been raped and asked if allegations had any "background". The Geriatrician changed mum's medications but did not pursue the rape disclosure.

[53] opalinstitute.org/inhershoes

The staff did not contact the Department of Health or police as part of their compulsory reporting requirements at this point. The Serious Incident Response Scheme was not in place at this point, but there was still compulsory reporting to the Department of Health.

We were not given information about sexual assault services to support mum or us.

The local Elder Abuse Service was not contacted.

The GP was called and wrote in mum's care record that she had "ideas of being raped", but no action was recommended. Mum was prescribed haloperidol to treat her agitation. There was a medication error, and she was given a drug overdose; she had four doses of Risperidone, became psychotic and was admitted to a hospital psychiatric ward.

Mum was transferred to the local hospital for her "behaviour" and treatment of her agitation. Her admission record noted that "polypharmacy is a significant issue" and staff wrote that she had "delusions of being raped" and was "preoccupied with thoughts of sexual assault." She was agitated on admission and was shackled by her ankles to her to a bed in the Emergency Department because she was so distressed. She was given more antipsychotic medication and the staff queried whether she might have a urinary tract infection. Six staff held her down to insert a urinary catheter for a urine sample. She was treated for a urinary tract infection.

We decided after mum's time in a psychiatric ward we needed to give mum a break from institutional care. So, Mum returned to her own home to live instead of returning to the aged care facility.

Because the aged care home dismissed mum's rape disclosure as hallucination, we didn't think about her being sexually assaulted either. It wasn't until later that we began to realise she may have been raped – and that the service providers weren't taking this into account. We blamed ourselves for not picking that up, but we trusted them to care for mum. We took our cue from them.

I wish I knew then what I know now. I now know that sexual assault happens in residential aged care and most of the victims are people with dementia. I now know that some service providers don't listen to people with dementia who report sexual assault – and that's not ok. Service providers need to listen and respond. People with dementia have the right to be safe from sexual assault in residential aged care.

We called the Aged Care Quality and Safety Commission and they investigated. As a result of that investigation, we received a letter from the aged care service, which said:

> *We apologise for not making the mandatory report in a timely manner [and that] as part of our continuous improvement program, following the complaint, all staff identified as not escalating the concerns have undertaken training on mandatory reporting of alleged and suspected assault.*

We lost faith in the aged care home and made the decision to care for mum at home. We had good support at home and mum was able to recover from the trauma. It gave us all time to recover from the trauma.

A friend put me in contact with a retired senior police officer, who agreed to review mum's notes and make up a timeline of what occurred. He contacted the police on our behalf to ask them to investigate the possibility that mum had been sexually assaulted. We had copies of mum's records from the aged care service and noted that some references to rape had been removed; we wanted police to investigate that as well.

The police said they would not investigate because mum had dementia. Not because of her level of cognition; but because of her diagnosis of dementia. I told them I thought that was outrageous. We got a copy of the police report, and it refers to mum's 'rape fantasies'. They dismissed mum's report of rape as 'fantasy'; they clearly need education as well.

There are so many questions left unanswered. Was mum raped? We don't know. Did the staff, including GP, geriatrician, residential manager, nurse practitioner, general manager, registered nurses, and care assistants handle mum's allegations appropriately? No, they didn't. Did the police handle it appropriately? No, they didn't.

Mum's rape allegations were never heard. She was never believed. My regret is I was unaware of the signs of sexual assault – but it should not have been our responsibility to make sure that the responses were appropriate.

It's not my responsibility to educate aged care service providers and the police about the sexual assault of people with dementia in residential aged care. People with dementia have the right to be safe from sexual assault in residential aged care – and it is our attitudes towards people with dementia that makes them vulnerable to sexual assault.

If we are not listening to people with dementia who report sexual assault, if we do not believe them – then we are part of the problem.

## Mapping responses to Sandra's disclosure

Over the next two pages we draw on the Dementia MAP to outline strategies to support Sandra and her family and to prevent sexual assault.

### *Element 1: Understanding sexual assault definitions and prevalence*

- The disclosure of sexual assault by a resident needs to be treated as a sexual assault
- Sandra's disclosure of sexual assault should trigger implementation of the organisation's sexual assault policy or protocol for responding to sexual assault.

### *Element 2: Clarifying sexual rights and consent*

- Sandra has the right to be free from sexual assault in residential aged care

- Residential aged care service providers have the responsibility to protect residents from sexual assault.

*Element 3: Assessing the indicators of sexual assault*

- Sandra repeatedly reported that she had been raped – staff need to recognise this as an indicator that she has been raped and respond with strategies for support and prevention
- Sandra's agitation, particularly around males, and some bruising on her arms are indicators of sexual assault
- Dismissing Sandra's agitation as an indicator that she was physically unwell missed the opportunity to support Sandra and prevent sexual assault.

*Element 4: Identifying the impacts of sexual assault*

- Sandra's agitation and distress are well-documented impacts of sexual assault
- Understanding the impacts of sexual assault can guide service providers understanding of what sexual assault victims/survivors need.

*Element 5: Complying with reporting requirements*

- Sandra's disclosure of sexual assault should be reported as a Priority 1 incident under the Serious Incident Response Scheme
- Sandra's family should have been notified immediately.

*Element 6: Providing immediate safety and support*

- Sandra's agitation and distress may settle earlier, and without sedation, if staff respond to her disclosure of sexual assault by
    - Believing her
    - Talking to her about the sexual assault
    - Telling her about the strategies to make her safe
    - Reminding her she was safe and working with her family to reinforce the message that she was safe

- Sandra and her family could be offered counselling through a sexual assault service. Sandra's family may be able to take her to the sexual assault service or arrange for a phone counselling session to work through her concerns
- Sandra and her family could be offered contact details for an OPAN Advocate to work with Sandra to ensure staff respond appropriately to her disclosure and that she feels safe
- Staff could work with Sandra and her family to develop a safety plan to support her.

*Element 7: Practicing Open Disclosure*

- Staff could communicate openly with Sandra and her family about their strategies to ensure she is safe and also that she feels safe
- The service could provide an apology from the most senior staff member as soon as possible.

*Element 8: Providing trauma-informed residential aged care services*

- The service could provide education to staff on the impacts of trauma such as sexual assault on victims/survivors and how to provide sensitive care
- The service could provide debriefing sessions for staff following Sandra's disclosure to check how staff are doing and what they need – and to demonstrate the support to staff that staff are being asked to provide to residents.

*Element 9: Recognising and reducing resident vulnerability*

- The service could provide education for staff on resident vulnerability to sexual assault and particularly the ways in which attitudes make people vulnerable, including the failure to respond to sexual assault disclosures
- Education needs to reinforce that a failure to respond to Sandra's disclosure makes her vulnerable to sexual assault in the future.

*Element 10: Protection, prevention and service Improvement*

- The service could implement a sexual assault policy to clarify the processes for responding when a resident discloses sexual assault
- Education should be provided to staff to ensure they understand how to implement the policy
- The service's risk management systems and processes should identify sexual assault as a high-impact, high prevalence risk and identify strategies to reduce this risk
- Talking to Sandra and her family and staff about the sexual assault disclosure can help services to identify how to prevent sexual assault of all residents.

## Useful information

- The #ReadyToListen webpage: https://opan.org.au/ready-to-listen/
- Dementia Alliance International: https://www.dementiaallianceinternational.org/
- Dementia Australia: https://www.dementia.org.au/
- Dementia Support Australia: https://dementia.com.au/
- People with Disability Australia: https://pwd.org.au/

## Support services

### Older Persons Advocacy Network (OPAN)

Information and advice line can connect you with an advocate from your local OPAN service who can advocate on your behalf. Call 1800 700 600 or check the website at: https://opan.org.au

### 1800RESPECT

1800RESPECT is the National Sexual Assault, Domestic Family Violence Counselling Service. They can provide you with information on your local sexual assault service for counselling and debriefing. Call 1800 737 732 any time or check the website: https://www.1800respect.org.au/

### 1800FULLSTOP

Fullstop Australia is here to put a full stop to sexual, domestic or family violence. They offer 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 Aged Care Quality and Safety Commission

The Commission assesses the quality of care and services in residential aged care and manages the Serious Incident Response Scheme or SIRS (all sexual assault must be reported to SIRS within 24 hours). You can contact the Commission to make a complaint about your sexual assault or the way it was managed. Call: 1800 951 822 (9am-5pm, Monday to Friday) or check their website here: https://www.agedcarequality.gov.au/