THE AGE

‘It’s not inappropriate’: Why adults with dementia are often shamed for sex

Lauren Ironmonger

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Gwenda Darling, a 71-year-old Palawa woman living with frontotemporal dementia, says she became hypersexual following her diagnosis in 2011. Recently, the pendulum has swung the other way, and Darling says she’s become asexual.

She says her evolving relationship with her sexuality is an important reminder that a dementia diagnosis doesn’t mean the same thing for any two people – and is ever-changing.

“My neural pathways around sexual desires may change in a month’s time … someday I might become interested again. But I don’t know that, I only know where I’m at today.”

A member of the Aged Care Council of Elders, Victoria-based Darling is a passionate advocate for the rights of those like herself. While she lives independently, Darling receives regular help from home care providers and often consults with residents in aged care.

Gwenda Darling, a 71-year-old Palawi woman living with frontotemporal dementia, is passionate about the sexual rights of those living in aged care. FLAVIO BRANCALEONE

Earlier this month, she spoke on a panel at the International Dementia Conference in Sydney about her experiences. She says that residents in aged care are all too often shamed for exhibiting any affection or sexual desire.

“It’s really important providers respect the rights of residents who wish to engage in sexual activities.”

An estimated 421,000 Australians live with dementia today, a number expected to increase to 812,500 by 2054, while 54 per cent of people living in permanent residential aged care live with the disease. As the generational makeup of aged care homes shifts, so too will the expectations of residents. Baby Boomers, the oldest of whom are now 78, are from the generation that was at the forefront of the sexual revolution.

“We were the era of free love,” says Darling. “I think we would still be engaging in sexual relationships as we did 50, 60 years ago if we weren’t stopped.”

Equally, she notes that many members of this generation – particularly women and LGBTQIA+ people – experienced sexual trauma in their youth and can be re-traumatised in places like residential care when they are shamed or disciplined.

Speaking alongside Darling was Dr Nathalie Huitema, a US-based sexologist and world leader in the development of guidelines for sexual consent for people living with dementia in residential aged care. She believes sexual ageism plays a role in how sexual behaviour is treated by aged care providers.

“A lot of people have that stereotype that older adults are asexual … and that’s not true, older adults are sexual beings.”

Indeed, contrary to what many people still believe, sexual libido does not diminish with age. A landmark study from 2007 found that age in and of itself has no impact on libido. Rather, things like illness, partner loss and certain medication – all which often come with ageing – can have an effect.

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>
> Dr Nathalie Huitema

Huitema says that this unwillingness to talk openly about sexuality with older members of society extends to the medical sector. She says healthcare professionals often neglect to discuss the sexual side effects of medications with older patients. Public health campaigns and aged care homes also often fail to talk to older adults about sexual health, reflected in the rising incidence of STIs among those over 55 in Australia.

Huitema wants to normalise sex in older adults and those with cognitive decline and see an end to the branding of sexual behaviour as "inappropriate" or "problematic".

"I always say the behaviour *is* appropriate; it's just sometimes [happening at an] inappropriate place or maybe at an inappropriate time, but it's not inappropriate behaviour per se."

Her research shows that older adults tend to have a more expansive view of what sex is, which can include everything from hand-holding to kissing.

"Young adults are usually focused on intercourse, and the sexual behavioural spectrum actually increases when people are older. So it's more about intimacy and touch and, of course, intercourse as well."

The question of consent

According to Huitema, our capacity to consent is commonly treated as black and white. A dementia diagnosis is, therefore, often seen as a blanket conclusion that someone no longer has the capacity to consent. But she says the reality is far more nuanced.

The part of the brain responsible for attachment, love and lust is quite rudimentary and does not require a high level of cognitive function. So, Huitema recently developed a model for sexual consent based on lived experiences to help providers optimise care for residents.

And as cognitive function in those with dementia fluctuates, so too does their capacity to consent.

"You might not be able to communicate your desires, wants and needs at a certain point in time, but that doesn't mean that you couldn't communicate [them] an hour down the line or in 10 minutes' time," says Darling. "It's living in the present."

"It's really important providers respect the rights of residents who wish to engage in sexual activities," says Gwenda Darling. FLAVIO BRANCALEONE

Olga Pandos is a lecturer in law and PhD candidate at The University of Adelaide who also spoke at the conference. She says Australian law defines decision-making capacity based on four key tenets: "That we can understand information that is relevant to a specific decision, that we can retain that information, that we can then use the information in the course of making our decision, and that we can finally communicate our decision by whatever means appropriate."

Explicit in these laws is the acknowledgement that the presence of fluctuating capacity doesn't mean someone lacks it.

"Importantly, this diagnosis does not mean that someone lacks decision-making capacity full stop," says Pandos. However, she says this is not always reflected in practice.

Pandos would like to see legislative and policy reform to better address the nuances of consent and dementia, but says this "needs to be accompanied by changes in attitudes, culture and practice in particular in the aged care sector and workforce education."

Sex and residential care

There are currently no national guidelines in Australia for responding to sexual behaviour in aged care. A La Trobe study from 2023 that surveyed 3000 residential aged care homes found that just over half had guidelines in place.

Ashley Roberts, a dementia consultant with The Dementia Centre, supports aged care providers in how best to respond to behaviour changes. He says they've noticed a steep increase in referrals for "sexual behaviour" in recent years.

“[But] what we’re finding is that when we go out to investigate those cases, quite often they’re being misinterpreted,” he says.

“They are just signs of people being affectionate to each other … any sort of physical interaction, whether it just be hand holding or hugging or giving somebody a peck on the cheek.”
Of course, there are genuine cases of unwanted affection, and sexual abuse in aged care is a genuine concern, stresses Roberts. But he says well-meaning staff, often fearful of legal repercussions or criticism from management or family members, tend to err on the side of caution, resulting in over-reporting. A lack of guidelines and training also means many workers don’t know how best to respond.

The Serious Incident Response Scheme (SIR), introduced three years ago, is a mechanism aimed at reducing abuse and neglect in Commonwealth-funded aged care facilities. But Huitema and Roberts both believe that a significant proportion of the approximately 50 reports under the SIR each week in Australia may be consensual.

As a new generation moves into the nation’s aged care homes, Roberts says guidelines and training need to change to better account for their more liberal views of sexuality, or the system risks becoming overloaded with illegitimate reports.

“Aged care has a certain archetypal resident in mind … and that ideal resident is rapidly changing, and he’s not going to be around for much longer.”

He says we need to get better at describing behaviour and distinguishing between wanted and unwanted behaviour.

“If we continue to label absolutely everything as a behaviour problem, then the genuine ones we need to be paying our attention to, like unwanted sexual behaviour, are going to get lost.”

The right to pleasure – and to take risks

“We need to be assisting people for pleasure in residential aged care,” says Darling, who spoke passionately on the panel about normalising masturbation and the use of sex toys for older people who want them.

“At the time of all that [climax], it clears the head, not only of pain but there are no thoughts racing, no depression.”

“Everybody does it, most of us see fireworks. Why should we be denying old people just because they’re in residential care?”

Darling adds that people with dementia have just as much of a right to make mistakes as anyone else, pointing to the Dignity of Risk Policy in aged care.

Huitema stresses that any consideration of the potential risks of sexual activity needs to be balanced with the potential benefits.

“I think it’s so counterproductive in health care to not go for the option where people experience better quality of life, an increase in wellbeing and in general health,” she says.

“But having the focus on that usually takes away the attention on autonomy, justice, and wellbeing, which are the three other principles of health care.”

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Lauren Ironmonger – Lauren is a lifestyle writer at the Sydney Morning Herald. Connect via email.
