LEGISLATIVE ASSEMBLY
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STANDING COMMITTEE ON EDUCATION AND COMMUNITY INCLUSION
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Submission Cover Sheet

Inquiry into Loneliness and Social Isolation in the ACT

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Inquiry into Loneliness and Social Isolation in the ACT

Submission from the Centre for Ageing Research and Translation (CARAT) at the University of Canberra

This submission is addressed to social isolation and loneliness among older people in the ACT, and specifically to those persons living with dementia and their care partners. Our submission is divided into two parts.

The first addresses matters listed under clauses (b) and (c) of the Inquiry scope, and the second to clauses (d) and (e).

Part 1: Matters pertaining to experiences of loneliness and social isolation and the personal and social costs associated with experiences of loneliness and social isolation.

As will be already well known to the Inquiry, loneliness is a risk factor for a range of negative physical, emotional, cognitive and social health outcomes. United States Surgeon General, Vivek Murthy recently described the hazards of loneliness as comparable to other health risk factors including obesity and tobacco use (Rowland, 2024). Loneliness and isolation are associated with poorer cognitive function among older adults (Shankar et al 2013).

General estimates of social isolation and loneliness in Australia run at around one in ten older people in regard to social isolation and between 15 and 20% experiencing loneliness (see Figure below) (Relationships Australia 2018). However, evidence indicates that rates of loneliness vary with gender, employment status, income, marital status, living arrangements, mobility, and physical and mental health (Relationships Australia 2018, Surkalim et al 2022). Older people are a very heterogeneous population.

> *Up to 50% of those aged over 60 are at risk of social isolation and approximately one-third of older people will experience some degree of loneliness later in life. Social isolation has detrimental effects on health, having been identified as a risk factor for all-cause morbidity and mortality with outcomes comparable to smoking, obesity, lack of exercise and high blood pressure. It has also been associated with decreased resistance to infection, cognitive decline and mental health conditions such as depression and dementia and with increased emergency admission to hospital, longer length of stay and delayed discharges.*
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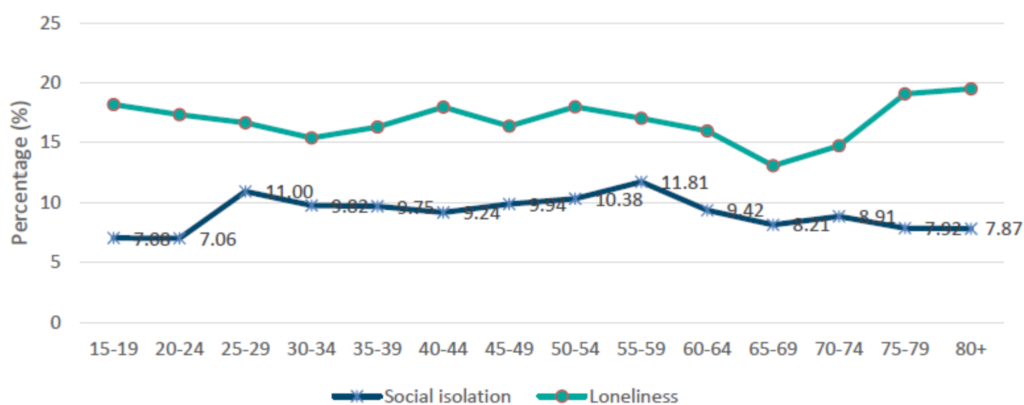
> Landeiro, F., Barrows, P., Musson, E.N., Gray, A.M. and Leal, J., 2017. Reducing social isolation and loneliness in older people: a systematic review protocol. BMJ open, 7(5), p.e013778.

The heterogeneity of older people

Older people may also belong to other vulnerable or potentially vulnerable populations, including people with physical, intellectual or psychiatric disability, people experiencing homelessness, people living in poverty, in their roles as carers, LGBTIQA+ people, Indigenous people, recently arrived migrants and refugees, and those who speak a language other than English. The heterogeneity of older people is important, not only because of the attributes described above, but because the age range of 60 and over spans such a broad demographic group – from people born in 1921 in the shadow of World War 1 and grew up during the Great Depression as children and adolescents, to those born in 1964 to an era of economic prosperity and manned space flights. This is significant not only in relation to heterogeneity, but also as evidence suggests that levels of loneliness decrease in the years leading up to 65, and then rise at older ages. The data series presented below stops at 80 and over, but it is likely that a further breakdown of the period from 80 to 100 would show further increases.

Figure 6. Proportion of Australians experiencing loneliness (ISS and emotional loneliness) by age, 2016, per cent



Source Relationships Australia 2018

The vulnerability of older people living with dementia

Loneliness and social isolation have been associated with a variety of negative health outcomes including cognitive decline, increasing the risk of developing dementia by 50% (National Academies of Science, Engineering and Medicine 2020, Guarnera et al 2023). Older people living with dementia, together with their care partners, are particularly vulnerable to loneliness and social isolation as they navigate changes to their lifestyle and relationships. A systematic review of

qualitative studies by Braun and colleagues (2019) cites numerous studies reporting adverse effects on levels of isolation from friends and family, loneliness, and opportunities for social engagement. A recent ACT needs assessment by Capital Health Network (2021) highlights the multiple demands on carers, including impacts to their social wellbeing. Developing and sustaining friendships following a dementia diagnosis is associated with better cognition (Balouch et al 2019), and having a poor social network is associated with serious adverse events (Dyer et al 2020).

> *'You become isolated, whether it's by choice, by design or by exclusion. The exclusion may be friends and relatives who no longer know how to treat you both. You isolate yourselves because of the difficulties in behaviour in going anywhere'*
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> Carer quoted in Stokes et al 2014

In the Sustainable Personalised Interventions for Cognition, Care and, and Engagement (SPICE) program, we see consistent evidence of the importance of social connection for people living with dementia and their care partners. SPICE acts as an important counterweight to the social isolation and stigma often experienced by people with dementia and their families. These problems usually worsen over time, particularly where the person develops challenging behaviours or where needs for support have been unmet (Braun et al 2019). In a recent interview, a carer explained how their 'old friends had fallen away' but the new connections established through SPICE had opened up a whole new world of social relationships.

The evaluation of the SPICE program is examining the feasibility, acceptability, and effectiveness of the new multicomponent, post-diagnostic rehabilitation intervention delivered by a multidisciplinary

> **What is SPICE?**
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> The Sustainable Personalised Interventions for Cognition, Care, and Engagement (SPICE) Program aims to delay the progression of dementia and improve quality of life through an active therapeutic rehabilitation program, which includes education and skill development for carers. The twelve-week SPICE Program consists of five components: (1) cognitive stimulation therapy; (2) carer social, emotional, and resilience education and capacity building; (3) physical activity; (4) Care of People with dementia in their Environments (COPE) Program and (5) dietary assessment and advice. Components one to three are completed weekly at the University of Canberra Hospital (or at Village Creek Centre, Kambah), across 2.5 hours on non-consecutive days. This is primarily a group based intervention with from six to seven dyads (a person living with dementia and their care partner) completing the 12 week journey together, but also includes components completed as a dyad which includes education and strategic planning for accessing social and support services.

allied health team. A suite of outcome measures are being used to evaluate changes in the quality of life, physical and cognitive function, and responsive behaviours of the person with dementia. In addition, changes in the quality of life, physical function, and self-efficacy of care partners are being measured. To date, the results of the SPICE intervention have been very positive for both people living with dementia and their care partners (See attachment A).

The SPICE program is unique as it facilitates the formation of friendships and bonds between group members thrust together as part of the intensive program design (D'Cunha et al 2023). Up to seven dyads spend a total of 60 hours together during each SPICE cohort. The majority of people with dementia in the SPICE program are recently diagnosed or are experiencing an increase in symptoms of dementia, which are interfering with their daily activities and ability to maintain their social networks. Through the psychoeducation and skill building provided during the program, both people with dementia and care partners share their lived experiences and are empowered to overcome some of the social isolation and loneliness they have been experiencing as they navigate their uncertain

Quotes from SPICE participants:

"I changed because of the people in the group." (Person with dementia)
"I just liked it being done. Because it was great to hear, and there were a lot of people there and I think that was nice. I really enjoyed it. I'm very upset that it's not there" (Person with dementia)
"He values I think the connection with the other participants because he can see that they are on a level footing. He enjoyed the laughter, he enjoyed the camaraderie and just the light-hearted banter." (Care partner)
"I think that [the person with dementia] has realised that he can make friends. So there was like a period of time when he finished working to when he started the SPICE group where he wasn't actually building connections with people at all. But since starting the SPICE program he has built connections and he's recognised that it's valuable. And I think that's overflowed into the other people we meet where he actually voluntarily connects with them." (Care partner)

Additional quotes can be seen here: https://www.hindawi.com/journals/hsc/2023/5395080/

Quotes from SPICE service delivery team:

"Oh it was just fantastic. To see the difference[s] in probably all of the six clients [people with dementia], just the development in them. The communication, the rapport that was built amongst the clients." (Allied Health Assistant)
"[They] took that upon themselves to create their own informal support network. And so, they would come and just sit and chat … they also talked about - whilst the dedicated education and psychological and emotional skill-building sessions were great - they found the informal learnings that they got from each other through their own lived experience and … not only the learnings, but the emotional support they got through that was highly effective." (Service Manager)

futures since dementia entered their lives. In our 2023 publication, social connection, engagement, and interaction were identified as key factors in the success of the SPICE program (D'Cunha et al 2023). People with dementia were seen to gain confidence by working on their communication skills in an environment that supported them in expressing themselves in a safe, inclusive and judgement-free environment. Care partners felt the regularity of interaction with other group members enabled the formation of friendships and bonds in ways that were not possible at other support services. Eight SPICE groups have now completed the program with another six scheduled and a significant waiting list in place for 2025 groups. All groups have self-managed different ways to stay in contact, such as through WhatsApp, regularly scheduled lunches at local clubs, day trips, and by attending pre-existing services as a group (for example, Dementia Australia Memory Cafes). Outcomes of the SPICE program, to date, emphasise the importance of being socially connected and engaged with a support network while living with and caring for a person with dementia.

Part 2: Matters pertaining opportunities for the ACT Government to support organisations and individuals to address loneliness and social isolation and improve social connectedness, and to integrate improved social connectedness into other areas of policy making

SPICE has been enormously helpful to the groups who have completed the program. An important and unexpected result has been the high level of group cohesion and group support that emerges, a key factor in addressing the social isolation and loneliness associated with living with dementia and caring for a person with dementia. But our SPICE participants are frequently asking us "what next?". The groups have been inventive in developing ways to stay in contact as outlined above , however we see an opportunity for a partnership between the University of Canberra and the ACT Government to provide continued support for participants through a program we are calling SPICE for Life. This 'post-SPICE' program is a less intensive and less costly intervention that will continue to support the cognitive, physical and social needs and well-being of people with dementia and their carers through cognitive stimulation therapy and exercise on a weekly basis, while also enabling opportunities for ongoing social connection. To do this, we propose the use of the University of Canberra student-led clinics, which would make use of an existing facility and help educate the next generation of clinicians – creating a virtuous circle. SPICE for Life would need funding support for the purposes of implementation and evaluation, and has the potential to establish a first-of-its-kind student-led interprofessional learning clinic that can be replicated for people experiencing other chronic health conditions.

Given the increasing number of people completing SPICE (200 people due to complete by end of 2024), there is scope for SPICE for Life to expand beyond the University of Canberra campus, with students leading groups in community halls in partnership with not-for-profit community organisations who have already expressed interest in the model. In addition, with SPICE at Home under development as part of an ACT Health Research & Innovation Fellowship, there will be an increasing number of people who could access SPICE for Life in 2025 and beyond. SPICE at Home aims to provide rehabilitation for people with dementia in their home, targeting those who cannot join a SPICE group due to inability to travel, living alone, English as a second language, or co-existing mental health conditions. Therefore, establishing and growing SPICE for Life will have ongoing community impact by not only increasing socialisation, but potentially reducing participants rate of cognitive and functional decline, as well as unnecessary hospitalisations and falls.

A briefing document on SPICE for Life at UC

Who will be the beneficiaries:

- People with dementia and their care partners will be able to continue receiving the benefits of SPICE once per week. There is overwhelming demand from previous participants who consistently ask, “What’s next?”.
- These benefits for people with dementia and their care partners will relate not only to clinical benefits, but help maintain and further develop the social connectedness that has been an unexpected but very welcome outcome of the SPICE program.
- UC Allied Health students will benefit from being involved in a first-of-its-kind interdisciplinary student-led program including students from Occupational Therapy, Clinical Psychology, and Sport and Exercise Science. Students will be supervised as part of their clinical placements. Over the course of one year, it is expected that at least 40 students will be exposed to working with people with dementia and their care partners. This will give students valuable experience working with this vulnerable population and may inspire them to pursue a career working with older people.
- In addition to providing leading edge post diagnostic care through SPICE, the ACT government has an opportunity to develop another Australian first by supporting the

development and implementation of SPICE for Life. It is well known that dementia services around Australia lack integration and an appropriate pathway following a dementia diagnosis. Having an option for clients who finish the SPICE program is the next key step in optimising dementia care for people living in the community and their care partners to prevent unnecessary hospitalisations, falls, and high use of ACT Health services.

What are the expected outcomes:

- Increased dementia awareness and reduced stigma among students.
- Higher number of student clinical placements with older people. Currently, the University of Canberra has excess student placements with younger populations and a lack of older person placements across disciplines.
- The program will be used as an exemplar for establishing an interdisciplinary student-led program that could be replicated for people with other health conditions.
- Improved quality of life of people with dementia, reduced care partner burden, and reduced risk of falls and hospitalisation.
- If successful, the SPICE for Life program could be expanded to scale up to more groups and also to add more clinical placements. If participants require further treatment, the University of Canberra Health Hub has student-led clinics in optometry, speech pathology, and physiotherapy. In addition, there is scope for Occupational Therapy students to do home visits as part of their clinical placements similar to what happens in the SPICE program.

How will this support and address disadvantage, health risks and isolation in ACT/Canberra region

- There are no dementia-specific programs in the ACT Health system other than SPICE. This provides a potential option for continued intervention after SPICE to maintain the benefits received and to continue being engaged in cognitive stimulation, care partner support, and exercise for both the person with dementia and the care partner.
- When people finish SPICE, there are no dementia-specific exercise groups that clinicians can recommend. Consistent feedback from previous SPICE care partners is that their loved one is unable to receive benefits from existing community-based senior exercise programs because they are not suitable for people with dementia, unlike the exercise program in SPICE which is designed and run with this group in mind. Remaining active can reduce their risk of falls and help to delay the progression of cognitive and functional decline.

- The vast majority of people with dementia who present at the Canberra Hospital have not received dementia support services in the community and only learn about what is available while admitted. There is an urgent need for more options for people with dementia to help them to remain independent in the community and able to be cared for at home for as long as possible by family members, potentially saving the health system billions of dollars.
- The improved awareness with students, academics, administrators, cross-industry partnerships (university, health services, NGOs), carers and their social networks will improve the 'dementia-friendliness' of our community and improve accessibility to other services, as well as aptitude of this population to access non-dementia specific services.

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