



Inquiry into social isolation and loneliness in Queensland

Community Support and Services Committee
Queensland Parliament

18 August 2021

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About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Community Support and Services Committee inquiry into social isolation and loneliness in Queensland.

Our submission is informed by the lived experience of people living with dementia, their families and carers.

Dementia Australia advocates for improvements in policy, resources and service delivery to ensure equity of access to quality health, aged and disability services that are responsive to the needs of people with dementia, their families and carers.

Historically, people living with dementia have not experienced full inclusivity within society. It is the case that the past decade has seen increased human rights recognition in the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD requires people with disability (including people living with dementia) to enjoy the same rights as everyone else, together with rights to autonomy in decision making, independent living, community inclusion, and liberty.

The challenge, however, is to shift attitudes, and design and deliver services that are flexible, innovative, appropriate and culturally safe to ensure people with dementia, their families and carers are well supported and included within the Queensland community.

Dementia in Queensland

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person's functioning. Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are 472,000 Australians living with dementia in 2021¹ and around 1.6 million people² involved in their care.

Specifically, in Queensland, there are an estimated 90,000 people living with dementia. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 207,000 people by 2058.³

Dementia is not a natural part of ageing. Although it is more common in older people, it can affect people in their 40s, 50s and even their 30s.⁴ Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 5,620 people living with younger onset dementia in Queensland. This number is expected to increase to an estimated 7,360 people by 2058.⁵

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.⁶

It is not widely understood that dementia is a progressive cognitive disability. It is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.⁷

¹ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016, Department of Health; Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), Global estimates of informal care, Alzheimer's Disease International; Access Economics (2010) Caring Places: planning for aged care and dementia 2010–2050

³ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

⁴ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁵ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

⁶ Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. no. 3303.0)

⁷ Australian Institute of Health and Welfare (2012) Dementia in Australia

Impact of social isolation and loneliness among people living with dementia, their families and carers in Queensland

Social isolation and loneliness are closely related concepts and have been found to predict premature mortality, depression, cardiovascular disease and cognitive decline.⁸ Not only this, but loneliness may contribute to cognitive decline through multiple pathways, including physical inactivity, symptoms of depression, poor sleep and increased blood pressure and inflammation.⁹

Dementia can have a profound impact on the social lives of people with dementia, their families and carers. Many people living with dementia have shared that they wished they had more social contact with people in the community.

People living with dementia, their families and carers have also told us that:

- banning or limiting essential visits in residential aged care has caused or is causing carers and families significant distress, especially for older or vulnerable carers for whom these visits are their primary source of social connection;
- some residential aged care facilities have not been able to offer person-centred, appropriate alternatives to essential visits (video conferencing is not always suitable for people with moderate to advanced dementia);
- some carers and families have experienced considerable resistance from aged care staff or difficulties in arranging essential visits; and
- limiting essential visits has resulted in poor physical and psychological outcomes for residents with dementia, including weight loss, agitation and accelerated cognitive decline.

People living with dementia, their families and carers who receive care across residential, in-home care and respite shared with us that the impact of diminished social connection throughout the various lockdown periods has been extremely challenging. Furthermore, of those people living with dementia, families or carers in the community, the vast majority referenced having difficulty in accessing emotional or psychological support.

“After losing my wife in March 2020, the day before Covid restrictions started, I have had many difficult moments. Without the assistance of my psychologist I'm not sure where I would be today. I lost all the support I was promised due to the lock down. I found it was a very stressful time.” Former carer

“The most challenging might be that she didn't get a visitor as regularly because it was impossible.” Carer

⁸ Smith, BJ and Lim, MH (2020) How the COVID-19 pandemic is focusing attention on loneliness and social isolation. *Public Health Res Pract.* 2020;30(2):e3022008

⁹ Harrington, K and Sliwinski, M.J (2020) The loneliness of social isolation can affect your brain and raise dementia risk in older adults, *The conversation.*

“So, a lot of homecare people are being so well looked after by the family, and then there’s a small proportion that doesn’t, that people don’t see the downside of stuff. I mean, there was a stage during the restrictions I felt really depressed, but then I have to look after him. He’s in a worse situation. If I don’t feel like cooking, he has nothing to eat. You get what I’m saying. I can’t do that to him.” – Carer

The interplay of COVID-19 on social isolation and loneliness

The COVID-19 pandemic has affected people living with dementia, families and carers in a multitude of ways. Like all of us, the routines of day-to-day life have been significantly interrupted. A less obvious but no less significant impact has been the adverse effect that physical distancing, restrictions and lock-down measures implemented in response to the COVID-19 pandemic have had on the physical, social and mental wellbeing of people living with dementia, as well as those caring for them.

People impacted by dementia already experience lower levels of social engagement, inclusion and connectedness within their communities. This, coupled with the restrictions enforced through the COVID-19 pandemic, has meant that people living with dementia, their families and carers are even more vulnerable to adverse mental health outcomes.

“One just must explore how dementia can be prevented? Don't smoke – (people are smoking more as a stress reduction aid). Stay at a healthy weight - (minimal exercise, motivation, fear(anxiety) and depression, eating more junk food or not the right food). Get plenty of exercise – (just not happening. Especially in lockdowns many older people are afraid to go out – fear of COVID and or breaking the law). Eat healthy food – (not being able to shop as often, lack of motivation, depression, could be factors here too). Manage health problems including diabetes, high blood pressure, and high cholesterol – (not able to see a doctor as easy – fear of catching COVID, not able to get there as easy – [no social contact to drop you off]). Stay mentally alert by learning new hobbies, reading, or solving crossword puzzles – (again lack of motivation or access not so available, libraries too are often closed. Stay involved socially – (not possible because of varied restrictions, can be helped if one has a computer and zoom, but may not be available to all for a variety of reasons).” Carer

In June 2020, Dementia Australia surveyed our network of Dementia Advocates (that is, people living with dementia, families and carers who work with Dementia Australia to elevate the voices of those impacted by dementia) about their experiences to better understand the impact of COVID-19. Combined with analysis of qualitative and quantitative primary research conducted by the research team at the University of Sydney between July and October 2020, and data obtained from the National Dementia Helpline, it is clear that COVID-19 has had fundamental and lasting mental health impacts for people living with dementia, their families and carers.

People living with dementia, families and carers have come to Dementia Australia with stories of loneliness, frustration, stress and fatigue. Families have highlighted their concerns

about the quality of care of their loved ones, the stress of not being able to see their family members living in residential aged care or in their own homes (where geography separates them), and the limited availability of services.¹⁰ Life is already challenging for many people living with dementia, their families and carers. The global pandemic and associated restrictions, including social distancing and isolation measures, has compounded the stress and anxiety experienced by many.

As people have gone into isolation, they have largely been cut off from the often already tenuous or limited social interactions, support services and meaningful connections that promote mental health and wellbeing. This has had demonstrable flow-on effects on the mental health of many Queenslanders, with people living with dementia, their families and carers especially vulnerable.

“My husband reluctantly went in to respite for a month, the day he went in I was advised that afternoon that he was in lockdown for 15 days. Of course he felt that I had left him there as he had no idea what Covid was.” Former carer

“The lockdowns decreased services and volunteer visitors to those living in the community and stopped family visiting to those in residential care. I have seen rapid progression of dementia because of fear, abandonment, isolation caused.” Former carer

Causes and drivers of social isolation and loneliness

People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This is inclusivity and should be embedded throughout the Queensland community and applied regardless of whether a person has a dementia diagnosis.

One of the biggest barriers to a human rights approach to dementia is that it is still poorly understood by the community, including by many people working in the health, disability and aged care sectors. There is an obligation for all levels of government, health, disability and aged care sectors and their workforce to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.

“Common causes of social isolation for people living with dementia and their families typically have significantly fewer relationships than the general public. Mainly due to friendships falling away fostered by stigma and discrimination and not understanding dementia. Other factors that may contribute the experience of being socially isolated, include having a comorbid disability, living alone, limited finance, impaired mobility, no family close by, never having married, transportation challenges, and divorced, separated, or widowed.” Carer

¹⁰ Dementia Australia (2020) The impact of COVID-19 on people living with dementia, families and carers - A submission to the Royal Commission into Aged Care Quality and Safety.

There are a number of barriers that prevent people living with dementia from being fully included in society, such as stigmatisation, invisibility, conflicts between safety and duty of care, and a lack of community support. Dementia Australia supports the findings in the *Safe and Just Futures* report, which advocates that the recognition of human rights for people living with dementia, their families and carers need to challenge current practice and begin from the premise that people living with dementia are full humans, equal to everyone else. This is necessary in order to prevent the ideas about dementia (which might be buried in seemingly apolitical and medical ideas about dementia) being transplanted into the way human rights are interpreted and applied on the ground. To this end, work needs to be done to improve sector and community views about dementia and support the development of communities that are inclusive and supportive to people living with dementia.¹¹

Many factors stop people living with dementia, being respected, promoted and realised. Some of the key barriers as identified by people with a lived experience of dementia include:

- unconscious bias;
- a lack of experience with people with dementia, which leads to misunderstanding, inaccurate assumptions and a failure to recognise their rights in one form or another;
- ignorance;
- poor education;
- low profile of dementia in the community; and
- low diversity literacy.

These barriers are linked, in their most extreme forms, to violence, abuse, neglect and exploitation because dementia is not part of most people's awareness until they need to consider it. This lack of consideration of how the needs of people with dementia differ can perpetuate negative treatment of them and the cycle of ignorance and disrespect. Additionally, as many people with dementia do not have a voice themselves (especially in advanced stages of dementia), these barriers to equal human rights and respect remain overlooked unless advocacy organisations and/or support is available and governments prioritise the needs of people with dementia, their families and carers.

“Firstly - Know the rights - Expect those with disabilities to have something to contribute and take the time to listen and comprehend what they are saying. Don't talk over the top of them or FOR them unless they ask you to. Have the Shire councils with a Disability Access reference group for all public works, have a Dementia Friendly Community be established and train the various shop owners, business people, care practices and care homes in the best inclusive practice. Lead by personal example of inclusion too.” Person living with dementia

¹¹ Dementia Alliance International (2020) *Safe and Just Futures for People Living with Dementia in Residential Aged Care* <https://www.dementiaallianceinternational.org/wp-content/uploads/2020/03/Safe-and-Just-Futures-Project-Report-for-Web.pdf>

Protective factors to mitigate social isolation and loneliness

An inclusive society allows for participation, respect and decision-making. It is more than equality of all people, it is about equity of access and for all people to feel safe to meaningfully participate in and contribute to society.

“The ability to be able to access the community and be involved in community groups and organisations. Being valued still, as a person, being respected and included. Being asked for my opinion and input.” Person living with dementia

“Inclusion means to me that I have the exact same rights as anyone else in society. That there are allowances and alterations, if required, in my society and environment to live alongside all other human beings. That people without disabilities value my rights to be able to live a normal life, as they do. That I have the same access to services as they do. That I should never have to explain why I need to be treated as everyone else.” Person living with dementia

“Being accepted, no matter what.” Former carer

“From a dementia perspective, inclusion means giving (better) recognition and acceptance of cognitive disability throughout societal structures, rules and behaviours, and making adjustments to support continuing participation in "life" and in the community.” Former carer

Specifically, what mitigates social isolation and loneliness, and promotes inclusivity for people living with dementia, their families and carers is a community anchored in respect. Having a commitment to value all people as equal, irrespective of their abilities, and being pro-active in anticipating appropriate requirements to meet their needs. This can include building supportive environments through design, for example, signage, ramps, colours used for the interior of buildings etc; and supporting people to support those who need assistance - be it advocacy, help completing daily tasks or accessing information.

“An inclusive community: * Does everything that it can to respect all its citizens, gives them full access to resources, and promotes equal treatment and opportunity; * Works to eliminate all forms of discrimination; * Engages all its citizens in decision-making processes that affect their lives; and * Values diversity.” Carer

A critical priority to mitigating isolation and loneliness in people living with dementia, their families and carers is for aged care providers and Queensland government to facilitate ongoing mental health and aged care support services.

Benefits of addressing social isolation and loneliness

The benefits of addressing social isolation and loneliness are extensive. Not only will it improve the health and wellbeing of the Queensland community, better support people living with dementia, their families and carers, but it will also positively impact the economy. There

are various negative flow on effects, as mentioned previously in this submission, that social isolation and loneliness can lead to.

“Not addressing it can lead to more hospitalization, emergency department visits, and nursing home placements. Addressing it lessens the risk of health issues such as dementia, stroke and heart disease thus reducing mortality rates in the community.”

Carer

“Less depression, slow progress of illness, longer life, happier people, less funding needed in healthcare.” Former carer

The majority of people with dementia live in a community. But many communities do not really understand what dementia is or how it can affect someone. This may lead to people living with dementia, their families and carers feeling socially isolated.

However, with the support of their communities, people living with dementia can remain socially included and connected. They can continue to engage in the activities that are important to them.

Small actions count towards making a big difference to the everyday lives of people with dementia. Dementia-friendly communities are inclusive suburbs or towns where people living with dementia are able to continue living the life they choose.

Creating dementia-friendly communities, improves access to social activities and opportunities for engagement including employment and volunteering. Each dementia-friendly community will look different but may include simple changes such as training staff to better communicate with people living with dementia, providing volunteering and employment opportunities for people living with dementia, and providing access to social activities.

“Respect for the individual. By having an inclusive community that is accountable for its actions. By having strong advocacy assistance if needed. By ensuring quality standards are maintained in all care environments i.e. home care and residential care. By ensuring appropriate checks are made of all places providing care and services to people with disabilities. By treating others as you would want to be treated yourself!” – person living with dementia

When people in the community come together as a dementia alliance, they create a more inclusive and welcoming place for everyone to live.

Preventing, mitigating and addressing the drivers and impacts of social isolation and loneliness across Queensland

Promoting an inclusive society is not simply about more funding. It is about collaboration within and across governments, sectors, communities, businesses and organisations. There needs to be prioritisation of:

- innovation – thinking outside the box to allow for dignity of risk;

- inclusion, participation and decision-making;
- training and building the capacity of the health, disability and aged care workforce to understand dementia and acquire the necessary skills, knowledge and capacity to deliver high quality dementia care;
- involving carers, families and advocates as partners in care and supporting them with decision-making and care planning;
- creating and delivering meaningful activities for people living with dementia to engage with or participate in;
- building supportive environments that are dementia-friendly and create a sense of homeliness, familiarity and participation;
- feedback and complaints systems that take people living with dementia seriously and facilitate their involvement; and
- building a culture that encourages an understanding of dementia and responding effectively to the needs of the person living with dementia, their families and carers.

“Providing real life work opportunities. Amending the tax laws on how much a person can earn without losing their pension. Making it easier to engage in volunteer work and maintaining active memberships of sporting or community organisations. Providing better transport options to attend these areas. Empowering community organisations to provide regular ongoing weekly support via a visit or phone call to check on isolated people. Also, provide support (vet bills, etc) for people to keep and maintain companion pets allowing them to have greater community access (bus, train, shops, etc.) with their companion animals.” Carer

A holistic and person-centred approach, including high-quality communication, with every individual is fundamental to improve inclusivity and recognise the human rights of people living with dementia.

Through transparency, accountability, greater collaboration and awareness raising activities, these things can be achieved through existing structures, frameworks and policies, but it also requires a shift in attitude.

“Where we accept all people for who and what they bring to their community.” Person living with dementia

This shift in attitude requires education. This is needed to bust the myths and misconceptions that exist that keep people living with dementia, their families and carers feeling excluded and isolated.

“You need a strong legal framework then a strong desire to enforce it. There must be strong education programs specifically aimed at sectors within the community such as employers, board members, children, the aged, specific cultural groups, etc. This education should include showcasing the value to the community that is provided by some disabled members of community but this must not imply that only the disabled who can demonstrate worth to the community are worthy of support and protection.” Carer

“Education first and foremost. Eradication of fear and stigma through learning encourages increased awareness, inclusion and lack of fear. I think we all want to be seen as the good guys and we benefit from helping. Everyone feels connected after performing a helpful act.” Former carer

“It’s really important to keep up the momentum of the disability sector gains in community understanding and acceptance and now focus on dementia being firstly a disability caused by a degenerative brain disease and not a diagnosis overshadowing / excluding by the old definition of dementia not be able to be changed in any way shape or form.” Person living with dementia

It is important to involve people living with dementia in the policy development process. They need to be given a voice and to be empowered to not only speak up if they experience adverse effects of loneliness and isolation, but to contribute ideas to facilitate the promotion of a more inclusive society.

“Stand up for unrighteousness. Advocate for inclusion. Employ people with a disability. Give them a voice - encourage them to speak up!!! Report inappropriate behaviour!!! Empower them.” Person living with dementia

“Have them first, their representatives second involved across all community life-beginning with full representation on all bodies and ideally using basic principles of co-design to re-engineer the community. Inclusion comes from within the community, not by a dictate or directive from outside.” – person living with dementia

An inclusive Queensland community that supports people living with dementia, their families and carers to remain connected has a focus on celebrating diversity and making people feel valued, welcome, integrated and included instead of feeling discriminated and isolated. People have an awareness and acknowledge unconscious bias, practice empathy and have an openness to learn. Inclusive societies are culturally aware and create a transparent environment in which all people feel empowered to express their opinions and ideas freely.

Priorities for a state-wide strategy to address social isolation and loneliness in Queensland

“Governments have to take the lead - to show the way. Whether by example, by laws, by regulations, by funding, by promotion, etc - they all help. Those with disability need support across a range of areas for them to be included.” Former carer

To promote greater inclusivity and combat social isolation and loneliness, in society for people living with dementia, there needs to be direct recognition and inclusion of these individuals in policy development and program design. This requires the leadership of governments to see the value lived experience perspectives have in improving the way care is delivered, and in creating supportive environments for people living with dementia. Some examples of good practice include:

- people living with dementia sitting on project specific working groups and/or steering committees;

- people living with dementia being consulted with about policy, programs, and/or service redesign that directly impact them;
- people living with dementia being listened to and their ideas taken seriously by decision-makers when they provide feedback, share insights, or provide guidance;
- seeing people living with dementia as equals and engaging with them from this perspective;
- promoting supportive and positive images, stories and contributions of people living with dementia, particularly in policy and program development;
- introducing dementia awareness training in school based programs; and
- not excluding people from consultation processes based on their dementia.

“Lead by example! From Federal - State to Local government bodies. Those that are most enabling and inclusive are at a local level - recognize and acknowledge this - then build upwards and outwards.” Person living with dementia

“There must be the five R’s: Right People, Right Training, Right Place, Right Time and Right Pay.” – Former carer

Another way social isolation and loneliness could be addressed is through giving people with dementia a stronger voice through advocacy organisations and mechanisms such as Dementia Alliance International (DAI) and Dementia Australia. These organisations are equipped to help people better understand dementia, its progressive nature and how needs can be best met.

This can be achieved through awareness campaigns that build broader understanding and target the community, which will help dispel myths, stigma and misunderstanding. This is effective because a key source of our learning about dementia is often through the media and social media.

To shift people’s attitudes and perceptions about dementia to be more respectful and inclusive, there needs to be information and education that portrays dementia in an accurate light. An example of how an awareness campaign delivered via media can help shift attitudes is in Dementia Australia’s [Keep the world open](#) campaign. This looked specifically at the discrimination faced by people living with dementia, who experience greater levels loneliness and isolation and urging people to stay connected with them.

Living with dementia changes how people experience the world. Dementia impacts people in different ways. People can experience changes to their memory, intellect, rationality, social skills and physical functioning. Many people experience other changes too. Changes in how people relate to them. People might stop talking to them, staying in touch and inviting them to things. That is not dementia, it is discrimination. The rights of people living with dementia are the same as the rights of others but the means of achieving inclusivity requires additional support from governments, workforce, communities, and the aged care and disability sectors.

Building on improving and increasing education about dementia, could be the development of supports and forums to provide greater and easier access to information. This reduces barriers and creates support environments for people to discuss dementia, gain an

understanding of what are appropriate responses towards dementia, and how to meaningfully engage with people living with dementia, their families and carers.

“Councils can support and encourage by simple things like ease of access, disabled parking, ambulant toilets and clear signage. How about families "adopting" someone in their own community that they engage with and visit once a week. Often contemporary families do not have access to grandparents and this would benefit both parties.”
Former carer

“Addressing the means for improving prevention / intervention strategies skills, abilities, and resources to refer vulnerable isolated people to caring helpful, community support services. Significantly raising awareness of the issues of loneliness and social isolation, training people from a young age with necessary skills to manage someone in distress from isolation and loneliness.” Carer

“‘Adopt a Senior’ the way you can Adopt a Road!! A society that looks after it’s elders is compassionate & caring. They can benefit greatly from the knowledge the older generation can pass on and could feel a sense of fulfilment and purpose from knowing they are supporting these people.” Former carer

“Well prepared programs/ interventions to offer trips to art galleries, sports, yoga meditation retreats, for both the person living with dementia and the carer.” Former carer

“To help those who are alone or have no English and create a pool of trained and paid Social Support workers and Lifestyle and Leisure coordinators as well as visitor Volunteers.” Former carer

Conclusion

The impact of social isolation and loneliness on the psychological wellbeing is as important as physical health, particularly for people living with dementia, their families and carers. Appropriate support, services and skilled professionals are needed to meet the mental, physical and emotional health needs of people living with dementia, their families and carers within the Queensland community to mitigate the negative impacts many have experienced.

The extent to which an inclusive society is realised in practice and in everyday life depends not only on the willingness of the Queensland government to change policy and regulatory frameworks, but on the support from the community for human rights – the attitudes and enthusiasm of community members, people living with dementia and those who provide advocacy and support.

People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This approach should be embedded in any targeted state-wide strategies. There is an obligation for Queensland government, to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.

Dementia Australia trusts the issues and recommendations identified in our submission assist the Inquiry Committee members to understand the issues people living with dementia, their families and carers face. We would welcome the opportunity for further consultation to ensure that the needs and concerns of people living with dementia, their families and carers are addressed.