



# **The Northern Territory Disability Strategy 2022-2032**

The Department of Territory Families,  
Housing and Communities

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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 Department of Territory Families, Housing and Communities consultation on the Northern Territory Disability Strategy 2022-2032.

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 Northern Territory community.

# Dementia in the Northern Territory

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 2021<sup>1</sup> and around 1.6 million people<sup>2</sup> involved in their care.

Specifically, in 2021, there are an estimated 1,990 people living with dementia in the Northern Territory, of which there are an estimated 240 people living with younger onset dementia. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 6,460 people by 2058.<sup>3</sup>

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.<sup>4</sup> Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 240 people living with younger onset dementia in the Northern Territory.<sup>5</sup>

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.<sup>6</sup>

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.<sup>7</sup>

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

<sup>2</sup> 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

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

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

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

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

<sup>7</sup> Australian Institute of Health and Welfare (2012) Dementia in Australia

## Vision, principles and outcomes

Overall, the draft Strategy is a sound document, which includes priorities that will create a more inclusive Northern Territory for people with disability, including people living with dementia.

The extent to which an inclusive society is realised in practice and in everyday life depends not only on the willingness of the Northern Territory 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.

The vision '*Territorians of all abilities are able to live life to their fullest potential and have quality services no matter where they live*' could be strengthened by including the terms 'inclusive' and 'timely.' As such, the vision could read '*Territorians of all abilities are included in the community, are able to live life to their fullest potential and have quality and timely services no matter where they live.*'

The principles in the draft Strategy are in alignment with other State and Territory disability strategies, and what is being explored through the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Dementia Australia supports the association with the CRPD principles for equality, access, rights, choice and participation.

The outcomes of the draft Strategy are appropriate and cover the breadth of issues important to people we have heard from who are impacted by dementia.

One suggestion for the second outcome '*Communities are inclusive and people with disability can engage, participate and contribute*' is to include the term 'meaningfully.' Resulting in the outcome being worded '*Communities are inclusive and people with disability can meaningfully engage, participate and contribute.*'

People with disability, including 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 draft Strategy.

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

Many factors stop people living with dementia, their families and carers, 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. Dementia Australia urges the Northern Territory government to include the needs of people with dementia, their families and carers in the draft Disability Strategy.

“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

## Priorities for the next three years

The priorities of the draft Strategy for the next three years should focus on creating an inclusive society that 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. Dementia Australia suggests setting the foundation of the Disability through respect building activities.

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

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. 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.

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, and disability 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...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 within the Northern Territory, 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 Northern Territory 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.

## **Making it happen**

“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 support the needs of people with disability, 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 - recognise 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

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 supportive environments for people to discuss dementia, gain an understanding of what are appropriate responses towards dementia, and how to meaningful 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.” – 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

“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

Appropriate support, services and skilled professionals are needed to meet the mental, physical and emotional health needs of people with disability, including people living with dementia, their families and carers within the Northern Territory 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 Northern Territory 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 with disability 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 the Northern Territory 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 Department of Territory Families, Housing and Communities to understand the issues people living with dementia, their families and carers face and consider them in the development of the Northern Territory Disability Strategy 2022-2032.