Dementia Australia™

The National Disability Strategy and National Disability Insurance Scheme Outcomes Frameworks

A submission to the Department of Social Services

18 December 2020

This page is left blank intentionally

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 in response to the public consultation for the National Disability Strategy (NDS) and National Disability Insurance Scheme (NDIS) Outcomes Frameworks.

Dementia Australia consulted people living with dementia, their families and carers about the Outcomes Frameworks. Their feedback forms the basis of our response.

Dementia is a disability

In 2020, an estimated 459,000 Australians are living with dementia. Of those, almost 28,000 people live with younger onset dementia (dementia diagnosed before the age of 65). Without a significant medical breakthrough, almost 1.1 million people will be living with dementia by 2058.[1]

Dementia is an umbrella term used to describe the symptoms of a large group of neurocognitive conditions that cause progressive decline in function. Dementia is more than memory loss - symptoms include impairments to speech, reasoning, visuospatial ability, emotional response, social skills and motor function. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is an incurable, terminal condition. However, many people with dementia, particularly those diagnosed in early stages, can expect to live with the condition for many years. It is imperative that we support people with dementia to live well, with dignity, respect and autonomy.

Dementia still lacks recognition as a progressive cognitive disability despite it being the single greatest cause of disability in older Australians (people aged 65 and over) and the third leading cause of disability overall.[2]

Inclusive and accessible communities

> "We want to participate in typical community events, sports, entertainment."

People living with dementia, their families and carers have the right to enjoy a varied, fulfilling community life. This includes participating in community events, sports, hobbies and cultural events. It is important to people living with dementia, their families and carers that the National Disability Strategy and the NDIS does not limit their ability to pursue their goals, independence or autonomy.

> "We want to go out free from stigma and know that, if needed, assistance is available."

Discrimination and stigma can limit or deter community participation. Dementia Australia's anti-discrimination campaign, "Keep the world open for people living with dementia" aims to

---

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

[2] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

address systemic marginalisation experienced by people impacted by the condition. To help break the stigma and marginalisation cycle, Dementia Australia would like to see a paradigm shift from a focus on lost capacity, to a society that centres the person living with dementia and empowers them to live with dignity, autonomy, freedom and purpose.

> “Dementia friendly areas should be included. It seems that people living with dementia are a ‘fairly shallow' fit in the general disability category.”

Dementia Friendly Communities is a program through which local towns, suburbs or shires to become more accessible to people living with dementia. Each dementia-friendly community action plan is unique, but will frequently explore people’s retail and hospitality experiences, public transport or local infrastructure, council services or public awareness. Dementia-friendly communities support people living with dementia, their families and carers to maintain their independence, mobility, interests and community connections.

> “Write to suit a variety of communication styles and languages. Take in to account our multi-cultural communities.”

Dementia affects people across our community – including different cultural backgrounds, ethnicities, religions, ages, genders, sexualities, professions and economic backgrounds. A person’s ability to communicate can change or become impaired as their dementia progresses. Bilingual individuals may revert to a language other than English as their dementia advances. Many people experience increasing difficulty with verbal communication or reading long documents. It is important that the assessment process is available in languages other than English and accessible to people who require additional communicative support or visual aids. An individual’s increasing needs should be factored into their package and assessment plan.

Recommendations

- That the Outcomes Frameworks assess the person living with dementia’s satisfaction with the way the NDIS and NDS has supported them to participate in community life
- That the Outcomes Frameworks includes indicators that can measure the impact of stigma and discrimination on people living with dementia’s ability to participate in community life
- That Dementia-Friendly Communities, or the underlying principles, are included in the Outcomes Frameworks as a measure of community accessibility and inclusion
- That the assessment process is accessible to people from culturally and linguistically diverse backgrounds and people with diverse communication needs

Economic security

> “To be supported in employment we need appropriately trained people to assist us in all of these areas, from DES, support workers and employers.”

With an ageing population and advancing retirement age, supporting people with dementia of working age is likely to emerge as a significant concern. Commonly mistaken to be an age-related condition, dementia is *not* a normal part of ageing. As many as 1 in 13 people living with dementia today have younger onset dementia. Many employers are unprepared for an employee presenting with dementia in their 40s or 50s, or even 30s.

In a workplace setting, early symptoms of dementia can appear as disorganisation and reduced performance. People with pre-diagnosed dementia have been accused of incompetency, inefficiency, or shunned due to socially inappropriate behaviour. They can be subject to verbal abuse or unfair treatment. Some people are ‘managed out’ of employment altogether. Workplaces are unable or unwilling to offer people living with dementia alternate duties or reasonable adjustments that would support continued employment, in breach of the Disability Discrimination Act 1992. Disclosing their diagnosis has resulted in termination for some individuals.

> “Help us engage in meaningful activities when employment is not an option.”

For some, their dementia may be too severe to maintain regular employment. However, this should not disqualify them from engaging in other meaningful pursuits. People with dementia should be supported through the NDIS and National Disability Strategy to participate in volunteering, mentoring or other personally rewarding and stimulating activities. The rate of participation in meaningful activities could form part of the person-centred indicators.

Recommendations

- That, in addition workforce participation, the Outcomes Frameworks investigates the reasons behind, or causes of withdrawal from paid employment
- That the indicators assess for self-reported experiences of workplace discrimination, exploitation, bullying or harassment
- That the Outcomes Frameworks assess whether the NDIS and/or NDS has supported the person living with dementia to achieve their volunteering or meaningful activities goals

Suitable housing

> “[It is] discriminatory to terminate NDIS support given to people living with younger onset dementia when, after the age of 65, they need to be admitted to residential aged care, which is the only viable alternative when they can no longer remain in their family home.”

Due to dementia’s progressive nature, people can expect their needs to increase over time. For many, the transition to residential care is an inevitability, despite most people preferring to remain at home. Several factors can drive an admission to residential care, including safety or wellbeing concerns, carer stress or fatigue, palliation, or insufficient home care support.

Suitable living arrangements are, therefore, a significant issue for people living with dementia, families and carers. NDIS packages need to account for, not just for a person’s current needs, but likely future needs. Allowances for home modifications is a good example of this. Suitable housing should accommodate a person with dementia’s current and anticipated need for assistance in the home.

> “The last point could read, "Live in a home that meets their needs, including a suitable care home for when their disability is terminal and the final stages are reached"

Moving house can be stressful, disorienting or reduce independence. It is preferable to maintain and adapt the familiar environment. Dementia-friendly housing differs in many ways from what we traditionally understand as accessible environmental design. Furnishings, colour schemes, lighting and layout can exacerbate symptoms of dementia as much as the architectural design of the building or space. A person with end-stage dementia may need to access Hospital in the Home style support if they are to avoid admission to residential aged care.

Dementia-friendly design principles offer guidance on how the built environment can empower and support people living with dementia. Dementia-friendly design principles are well placed to form part of the Outcomes Frameworks’ accessibility measures – both in private homes and in institutional buildings.

Recommendations

- That the Outcomes Frameworks measure whether the NDIS and NDS has enabled the person to access suitable housing or required modifications to their existing home
- That the indicators reflect the changing needs of people with progressive and/or terminal disabilities
- That the Outcomes Frameworks assess whether the person’s package is supporting the person to achieve their housing goals
- That the Outcomes Frameworks incorporate dementia-friendly design principles into the accessibility indicators

Health and wellbeing

> “The progression of dementia is far more unknown than other areas of disability. Living with dementia in itself is a unique entity and so much harder to generalise, I think.”

People living with dementia, their families and carers report that many health professional and support workers have a poor understanding of the symptoms, trajectory and types of dementia. People can experience a variety of increasing symptoms and impairments, depending on the area of the brain affected. These symptoms can involve memory recall, perception, executive function, emotion regulation, continence and motor function. People with dementia may also experience impacts on their mental health, such as depression, paranoia, hallucinations and delirium.

It is vital to the health and wellbeing of people living with dementia the professionals involved in their care are educated on dementia, can identify and anticipate their needs and confidently arrange the necessary services and supports.

> “We want trained and qualified workers to meet our specific needs. We want choice and control over our health and wellbeing and the right to not feel coerced by health professionals into something we do not want to have done.”

Maintaining choice and control is important to people living with dementia, their families and carers. The ability for individuals, or their carer or advocate, to seek out preferred health professionals or change providers if the therapeutic relationship breaks down was cited as missing elements of the provisional Outcomes Frameworks. The right to consent to, withhold, or explore alternative treatments, without repercussion or pressure from medical professionals, was raised by people living with dementia, their families and carers.

> “Happy and healthy seems a little trite. Being treated as an individual, holistically, is important.”

Dementia’s terminal prognosis and limited treatment options has led to a pessimistic view of what it means to live with dementia in some health professionals. Well-intentioned advice given on diagnosis to get ‘their affairs in order’ and prepare for the end of life disempowers people with dementia and reinforces a deficit-focused attitude.

This outlook can spill over into all aspects of a person with dementia’s care. Unlike many other disabilities, people with dementia are rarely offered rehabilitation or recovery-based services. Concerns or misunderstandings about legal capacity or competency can lead to people with dementia losing control or excluded from decision-making.

It is important that people living with dementia, their families and carers can access care and support that is enabling, empowering, person-centred and respect. Recipients of the NDIS, and people living with dementia, families and carers more broadly, should feel confident that the system is equipped to accommodate their unique needs and help them live well with dementia.

Recommendations

- That NDIS assessors and providers are equipped with the necessary skills to support people living with dementia to live well
- That the Outcomes Frameworks assess the person’s level of satisfaction with their care in a way that does not expose them to actual, or fear of, reprisals or coercion
- That people living with dementia remain in control of medical and lifestyle decisions, or supported to participate as much as they are able
- That people living with dementia should not be excluded from rehabilitative or recovery-based support, as part of a holistic wellbeing plan

Rights, protection, justice and legislation

> “The numerous ‘charters of rights’ that have been prepared mean nothing. Until these rights are legislated and adhered to, the abuse continues.”

Based on international evidence, up to 10 percent of older Australians experience elder abuse in any given year, with cases of neglect possibly even higher. People with cognitive impairment, like dementia, are at increased risk. A person living with dementia may not understand that abuse has taken place, be able to recall the abuse, or be able to report to the proper authorities. Their accounts may also be dismissed as unreliable.

We recommend that the Outcomes Frameworks include an indicator to detect the presence of abuse, neglect or exploitation. Where abuse, neglect or exploitation is discovered, swift action should be taken to protect the person living with dementia from further harm. People living with dementia, families and carers want stronger protections from abuse and harm in institutional and health care settings.

> “Have a system in place where police involvement that has occurred due to a person’s disability is flagged and a designated contact person could be contacted in the first instance. This could prevent escalation of some situations and allow behaviour management plans to be followed.”

There are two common situations where a person with dementia, their family or carer might have an encounter with emergency services. The first scenario is where a person living with dementia is reported as missing or presents to emergency services in a state of confusion or delirium. The second scenario is where a person experiences an escalation of symptoms that manifest as aggression or anti-social behaviour. Emergency services should be equipped with the necessary skills to assess a person for possible dementia and appropriately manage the situation.

Recommendations

- That the Outcomes Frameworks include indicators that will identify the presence of physical and/or financial abuse, exploitation and neglect
- That people living with dementia, their families and carers experience appropriate, respectful encounters with emergency service providers

Learning and skills

> “How about ‘return to education’ rather than ‘move from school’? Those words dismiss a mature age person who has acquired a disability later in life.”

As discussed previously, people living with dementia can be excluded or deterred from support that encourages them to live well. This can extend into whether or not people with dementia are encouraged to pursue personal goals and growth, such as undertaking further learning or study. People living with dementia, families and carers approve of learning at any age principles and believe that the Outcomes Frameworks should use empowering, inclusive language that supports people of any age or condition to pursue further learning should they wish.

> “Provide additional learning supports to facilitate successful learning outcomes”

People with dementia are able to undertake higher education with the right assistance. Educators can support a person to achieve their goals by tailoring the course or content to meet the individual’s needs – for example, using hard copies rather than screens, additional visual aids, or a teaching aide. NDIS providers can enable greater independence and freedom to learn by allowing for transport to and from classes as part of an individual’s plan. Retraining after diagnosis to pursue volunteering or achieve other personal goals should also be a feature of this area and, thus, reflected in the indicators.

Recommendations

- That the language used in the Outcomes Frameworks does not exclude or minimise mature learners or people seeking education later in life
- That people living with dementia are able to access the appropriate support to achieve their education goals

Personal and community support

> “Understand that people living with dementia can be somewhat different to other people with a disability and we may have need quite different supports and services.”

Progressive neurological conditions like dementia run counter to what we commonly understand about disability. Unlike ‘static’ physical or neurological conditions, the symptoms of dementia will increase steadily over a number of years, resulting ultimately in the person’s death. Successful engagement between the NDIS, the National Disability Strategy and people affected by this condition requires a nuanced and flexible approach operated by specially trained professionals.

Predicting and making accommodations for future needs is imperative when designing a plan for people with a progressive condition. Supporting the person to undertake future planning of their own – in an advance care directive and appointing enduring powers of attorney – is also important. Measuring the person’s satisfaction with their plan would provide a valuable insight into how well the NDIS is addressing a person’s needs.

People living with dementia want to access services and supports that will help them to live full, meaningful lives that are delivered in a respectful and flexible way.

Recommendations

- That the Outcomes Frameworks measure the person’s ability to access the services they need to achieve their goals and live well
- That the Outcomes Frameworks does not discriminate against people with progressive and terminal disabilities

Implementation of the Outcomes Frameworks

In terms of the Outcomes Frameworks implementation, there are a number of ethical issues that should be considered. Firstly, it is important that the consultation or assessment process is designed in a way that empowers people with dementia to participate as much as they are able. It should be acknowledged that, in some cases, families and carers, mostly from a place of concern and good intentions, ‘gate keep’ access to people living with dementia or under-estimate their ability to participate in these types of activities. We also know that carers or proxy participants are more likely to rate satisfaction or approval higher than the recipient.

> “The measurement of the outcomes are difficult if not impossible in some cases. There needs to be more support and governance to achieve any of these. There needs to be Special Investigator of similar, as suggested by the Aged Care Royal Commission.”

There was reservation expressed by people living with dementia, families and carers as to how the sub-outcomes would translate to measurable data. It was also recommended that the evaluation process been overseen by an independent person or agency.

> “I feel that there should be a system where disability payments are reviewed on a yearly basis to help recipients live better according to their lifestyle.”

People living with dementia benefit would benefit from annual reviews and assessments due to their fluctuating and increasing needs.

Recommendations

- That the Outcomes Frameworks implementation is overseen by an independent body to reduce the risk of bias or conflict of interest
- That the implementation of the assessment process considers the needs of people living with dementia and enables them to participate to their full capacity
- That the measurements are regular and flexible enough to track whether the NDIS and NDS are meeting people with dementia’s increasing needs