



Inquiry into the purpose, intent and adequacy of the Disability Support Pension

A submission to the Senate Community Affairs References Committee

June 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 Senate Community Affairs References Committee inquiry into the purpose, intent and adequacy of the Disability Support Pension (DSP). Our submission has been developed in consultation with people living with dementia, their families and carers, as well as Dementia Australia staff members.

Our submission specifically addresses two items in the terms of reference:

- b. the DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal; and
- g. the adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations;

Summary of recommendations

Dementia Australia recommends:

- Centrelink staff and assessors receive dementia education
- DSP claims of people with a confirmed diagnosis of younger onset dementia are fast-tracked to ensure they are not unnecessarily referred for a job capacity assessment and can receive timely financial assistance
- the DSP be increased to enable people to maintain an acceptable standard of living

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as 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. There are an estimated 472,000 Australians living with dementia in 2021¹ and around 1.6

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

million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.⁴

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability burden in older Australians (those aged 65 and over) and the third leading cause of disability burden overall.⁵ Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people, but it can affect people in their 40s, 50s and even their 30s.⁶

The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 28,300 people living with younger onset dementia in Australia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.⁷

The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia, their families and carers.

Younger onset dementia is difficult to diagnose, often taking three to five years and is under-recognised, resulting in community ignorance and stigma. This can result in delays in accessing necessary supports (including the DSP) and also means that dementia programs, primarily designed for older people, do not meet the needs of people impacted by younger onset dementia, who are seeking to maintain active and engaged lives.

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 The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

⁴ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

⁶ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁷ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

Younger onset dementia has a profound impact on individuals as well as their families, carers and friends. Most people living with younger onset dementia will experience one or more of the following:

- problems with language and forgetting words;
- losing track of time and place, so they may forget whether it is morning or afternoon, or may become lost in their own street;
- showing poor judgement, so they may find it hard to drive a car or they may buy things they do not need;
- problems with abstract thinking, so they may not know what the numbers on their bank statement mean;
- losing or misplacing things regularly; and/or
- changes in mood or behaviour.

People with younger onset dementia can also experience changes in personality, depression, anxiety, hallucinations and aggression. The severity, type and frequency of these symptoms get progressively worse over time, requiring an increased amount of support. Significant changes in needs can occur rapidly and without warning.

The impact of dementia on younger people is quite different than the experience of older people with dementia. People living with younger onset dementia, their families and carers often face the following challenges:

- impact on employment as people are usually still in the workforce and may be the primary income earner (affecting a family's finances);
- disruptions or changes to family relationships and dynamics, especially carer 'burn out';
- isolation and a disengagement from everyday activities long before the condition requires them to; and
- difficulties accessing appropriate services and supports as they find themselves caught in the gaps between the disability and aged care systems.

The DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal

The DSP can provide much needed financial support for people living with younger onset dementia. Yet the assessment and determination process can be overwhelming, confusing and distressing for people living with younger onset dementia, their families and carers.

“Assessment process took an extremely long time. Staff have very limited knowledge of dementia and the support needs.” Person living with dementia

“Applying for the DSP can be quite a gruelling and confusing process for many people living with younger onset dementia.” Dementia Australia staff member

People impacted by younger onset dementia report varying experiences with Centrelink staff during the process.

“I supplied medical evidence from my doctor and specialist. The assessment wasn't bad as they took one look at me and agreed that I wasn't in a good place.” Person living with dementia

Generally, though, there is a lack of understanding of younger onset dementia which impacts negatively on the experience.

“To get it [DSP] my husband had an interview with someone from Centrelink. I was unimpressed with this person as every time I mentioned something about it or he read something in a report from doctors, he had these problems. It really infuriated me. He also disputed the report from neuropsychologist, he could do it better. I didn't want to jeopardise the chances of getting the pension so didn't make a complaint. It came through. Very distressing at the time. Officer knew best, he could do it better, and his memory was bad etc. [It was] all about him, not my husband.” Carer

“My late husband had very early onset Alzheimer's disease, of which Centrelink staff had no understanding of. Whenever we dealt with the department, we felt with that we were making up this disease because of the age of my husband...The entire experience of applying for and being granted the DSP was a nightmare and increased my stress during an already stressful time.” Former carer

Dementia Australia recommends that Centrelink staff and assessors receive dementia education. Dementia Australia's Centre for Dementia Learning (CDL) is the leading national provider of dementia education and offers a wide range of courses and professional development programs for professionals working with and supporting people living with dementia. CDL staff could develop a specific education program for Centrelink to ensure that staff understand the complexities and nuances of younger onset dementia and facilitate a learning experience that inspires staff to change their practice.

Despite having a permanent, progressive and terminal disability which has required them to cease employment, some people living with younger onset dementia still must unnecessarily undergo Job Capacity Assessments. This process can be very distressing and traumatic.

“Not make it so difficult... Have dementia as a listed disability not requiring so many hoops to jump through as it is a degenerative disease! It is not a disease you can get better from.” Person living with dementia

The functional capacity of a person living with dementia can fluctuate from day to day and within a day. An assessment conducted over short period of time may not adequately capture the extent of disability and functional impairment. A person with dementia could be deemed ineligible for the DSP if the assessor does not have a thorough understanding of dementia.

“It was very difficult. I was aged 60 when I was diagnosed and left work. I had to wait 9 months before I could apply for Centrelink benefits. Because Centrelink did not understand dementia, I was first assessed as been able to work for 15 hours per week and the DSP was rejected. I had to appeal and obtain specialist reports and finally my application was accepted. All this process took about 6 months to finalise.” Person living with dementia

Dementia Australia recommends that the DSP claims of people with a confirmed diagnosis of younger onset dementia are fast-tracked to ensure they are not unnecessarily referred for a job capacity assessment and can receive timely financial assistance.⁸

The adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations

As previously outlined, people living with younger onset dementia, their families and carers can experience considerable financial stress as a result of the diagnosis and subsequent impact on employment. While some can obtain early access to superannuation, others are not able to or do not have substantial superannuation funds.

“My mum was still working when she got dementia; it was a real drop plus no super provision. You are forced into poverty, especially if you are still paying a mortgage.”
Former carer

The DSP, therefore, is a financial lifeline for many people living with younger onset dementia. However, some believe that the amount provided is not adequate and should be increased.

“As we are on DSP and I’m on Carers Pension I feel we do OK. I’m not sure if someone was only on DSP whether it would be sufficient.” Carer

“It is right for me but I also get a part pension from Commonwealth Super. I know of others where it is not enough particularly if you still are paying a mortgage and your partner has to work to support the family.” Person living with dementia

“Hopelessly inadequate just to get by!” Carer

Dementia Australia recommends that the DSP be increased to enable people to maintain an acceptable standard of living.

⁸ As per Department of Social Services guidelines available at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/disability-support-pension-dsp-better-and-fairer-assessments/fast-tracking-disability-support-pension-claims-for-people-with-profound-disability-or-terminal-illness>

Conclusion

It is critical that the process of applying for the DSP is streamlined and works effectively for people with younger onset dementia to enable them to receive much needed timely financial support.

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