Dementia Australia detailed comments and references related to the Australian Government’s response to Senate Community Affairs References Committee report: Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia

The care and support for people living with dementia remains the biggest social and health challenge facing Australia and the world. Dementia is now 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 years¹.

Dementia is a terminal condition that affects people’s abilities and memories and has a profound impact on the individual and their loved ones. It is surrounded by stigma and misunderstanding, isolates people, their families and carers from social networks, and carries significant social and economic consequences.

In the three years since the Senate Community Affairs Committee tabled its report and 18 recommendations, much has changed across the dementia care landscape, and not all of these changes have been positive.

The Government’s response to the report has noted and supported in principle most of the recommendations. Their response outlines various activities spread across the breadth and depth of the aged care, disability and mental health care systems, however the fact remains that these are complex systems that are challenging to navigate.

People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to those living with dementia is worse than the care delivered to any other vulnerable group.²

While the Government has outlined the priorities and actions under the National Framework for Action on Dementia 2015-19, the reality is that dementia is not given the priority support it needs as a chronic disease that is well on the way to being the leading cause of death in our country. Health, aged care and disability services reforms over recent years have been increasingly based on the belief that supporting people impacted by dementia should be part of core business for service providers. However there is much to do before this rhetoric becomes a reality.

Key response areas

1. Younger Onset Dementia key Worker Program (YODKWP)

We are particularly disappointed to note that the Government does not support the ongoing funding of the Younger Onset of Dementia Key Worker Program.

The YODKWP has been a crucial element in the sustained provision of care and support for people affected by younger onset dementia across Australia. The program aims to improve the quality of life for people with younger onset dementia, as well as their families and carers, by

² Australian Commission on Safety and Quality in Health Care (2013). Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review, ACSQHC, Sydney
providing them with a highly skilled key point of contact with whom they can develop comprehensive strategies that optimise their engagement with support and care options.

It is estimated that over 25,000 Australians under the age of 65 live with younger onset dementia (YOD). These are adults aged in their thirties through to their sixties; on rare occasions there are some in their twenties. The number of people living with YOD is expected to increase to over 42,000 by 2050. Aboriginal and Torres Strait Islander people are over-represented in this cohort as they experience dementia at a rate 3-5 times higher than the general population, often with symptoms starting younger. Thus the Committee’s recommendation in 2014 to increase the funding and expand the YODKWP was made in consideration of these stark prevalence statistics. Since then, the complexity of the multiple systems that people living with younger onset dementia have to navigate has only increased, with families and carers falling between the cracks of the disability and aged care systems. Dementia Australia has outlined the many issues people with YOD face in accessing the NDIS through our submissions to the Productivity Commission on the issue.

The Government’s response notes that the “Transitioning to the NDIS will provide the opportunity for Dementia Australia to receive significantly more funding whilst providing services to eligible people with younger onset dementia.”

Dementia Australia’s paramount concern is the lack of appropriate care and support for people living with YOD and their families and carers through the NDIS. The overwhelming feedback from individuals impacted by dementia in the modern world of consumer directed care is that support to navigate the system is imperative. This need is especially acute for people living with dementia and their carers, who often report difficulty in identifying what services are relevant, how they are delivered and how consumers can access them. This approach has also recently been highlighted through David Tune’s Aged Care Legislative review, which has highlighted the need for the introduction of “aged care system navigator[s] and outreach services to assist consumers who have difficulty engaging through the existing channels.”

The key workers represent a highly skilled health workforce and include nurses, social workers, physiotherapists, psychologists, occupational therapists, and diversional therapists. This multi-disciplinary team adds value to client support and strategies developed due to their broad range of knowledge, skills and experience. This approach will not be replicated under the NDIS.

From mid-2018, the primary point of support for people with younger onset dementia (YOD) will be the National Disability Insurance Scheme (NDIS). The NDIS alone as the ‘primary’ point of support for people with YOD is ill-informed and is not reflective of the needs of consumers, carers or experts in this area and will lead to significant gaps in services for people with younger onset dementia in the community. It is predictable that this decision will lead to people seeking access to residential care services earlier at a significant cost to Government. We have already raised concerns in October last year when the NDIS announced an intake halt on new participants into the scheme in the ACT.

While the Scheme presents some opportunities, it also poses significant challenges, as it caters for people with disabilities aged under 65 and has not been set up to cater for people with dementia or ageing-related conditions. This has especially been the case in its early days and support is

4 Alzheimer’s Australia (2014). Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research
inconsistent nationally. The ultimate risk for people with YOD is that they will end up in residential aged care prematurely.

Dementia Australia reiterates its call for the expansion of the YODKW program from a national network of 40 workers to 55 and continuing the program on a temporary basis for two years (until 2020), a move which will assist in a measured transition to the NDIS and ensure the widely reported existing gaps in NDIS service delivery are better addressed, especially for these vulnerable Australians.

2. Behavioural and psychiatric symptoms of dementia (BPSD)

Behavioural and psychological disturbances are often an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear).6 Most people with dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some stage during the course of their illness.7 Environmental factors can also contribute to BPSD, including too much stimulation, lack of privacy or an institutionalised like environment. Staff practices may also provoke behaviours. In many cases BPSD can be prevented through effective management of these contributing factors.

Individuals with severe BPSD who are ambulant often require specialised care. The care required by this group overlaps considerably with older individuals who have behavioural and psychiatric symptoms related to mental health conditions. Both groups require access to specialised ‘psycho-geriatric care’, although the underlying cause of their symptoms may be different. The National Health and Hospital Reform Committee8 identified access to psycho-geriatric care as an area that needs reform. “As a matter of some urgency, governments must collaborate to develop a strategy for ensuring that older Australians, including those residing in aged care facilities, have adequate access to specialty mental health and dementia care services”.

The report by the Psychogeriatric Care Expert Reference Group was also considered by the Ministerial Conference on Ageing in 2009.9 It carefully documented a framework for service planning and care delivery for people with psychogeriatric disorders. The framework included:

1. Integration at all levels within the broader health care system with appropriate facilities to assist older people with BPSD and/or mental health issues.
2. Ongoing access to and utilisation of specialist clinical expertise and care.
3. Appropriate assessment mechanisms and placement to ensure best ‘client fit’.
4. Appropriate staff levels and skills mix across the continuum of care.

The Ministerial Conference endorsed that framework.10 However this endorsement has not resulted in many practice changes on the ground level. Dementia Australia has outlined some of these barriers and issues in our response to the Government’s Review of regulatory activities applying to quality of care in residential aged care facilities.

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10 Communiqué issued on 15th December 2010 by the Ministerial Conference on Ageing in 2009 endorsed framework for service planning and care delivery for people with psychogeriatric disorders.
There is also emerging evidence that restorative and rehabilitative approaches to care for people with dementia may assist with BPSD.\(^\text{11}\) Active restorative and rehabilitative activities, such as recreational and daily living activities, have been associated with improvement in mood and behaviour.\(^\text{12}\)

In Dementia Australia’s view, comprehensive assessment and a focus on learning the language of dementia – observational techniques to assess how the person communicates pain – are required across the regulatory framework to ensure better management of BPSD.

Therefore, learning pathways are needed across the country for care staff to develop knowledge, skills and emotional intelligence, from basic level to advanced practice level across dementia. Government and aged care service providers have a shared responsibility to develop and fund education and career pathways for the aged care workforce. To this end, Dementia Australia encourages the federal government to maintain a commitment to supporting better ongoing education and training to develop and sustain a workforce skilled in dementia care especially for the aged care workforce.

### 3. Residential aged care accreditation standards

Consumer and provider experience tells us that there are still significant steps that need to be taken for quality dementia care and support to become an intrinsic part of health, aged care and disability services. This is especially so for marginalised or disadvantaged communities where their experience is often characterised by unacceptably long delays in diagnosis, poor access to treatment and lack of choice and quality in residential and community care. The increase in instances of poor quality and adverse outcomes for consumers such as Oakden Older Persons Mental Health Service is evidence demonstrate that much more needs to be done to support people living with dementia across aged care.

We also note the Government’s response to the Committee’s recommendations around improvement of current accreditation standards. As we have noted in our response to the Government’s Review of regulatory activities applying to quality of care in residential aged care facilities, there is evidence that the needs of people with dementia are not being fully supported through current mainstream aged care services.

Although quality should encompass individualised care, no matter what the requirement or how specialised the care need, we are concerned that dementia is not being adequately addressed through our current and draft regulatory/quality systems. For instance, it is concerning to note that the draft aged care quality standards\(^\text{13}\) do not acknowledge or consider the high risk and prevalence of dementia and associated cognitive decline, despite more than half of all residents in residential aged care having some form of dementia and despite the clear need for providers to have specialist capacity to manage dementia appropriately.”

While Dementia Australia acknowledges that people with dementia will always need to be supported by mainstream services, it must be recognised that although dementia is a core part of aged care, it is not enough to rely on the provision of mainstream services to adequately provide for the needs of people with dementia. Instead there must be an approach that combines building

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capacity in mainstream services to provide quality care for people with dementia, along with the integration of specialist dementia services to support mainstream services where required.

We need a renewed and sustained focus on dementia right now for the hundreds of thousands of Australians impacted by the disease every day and to prepare for what we as a community face in the years ahead.