

YOUNGER ONSET DEMENTIA: BRIDGING THE GAP



ALZHEIMER'S AUSTRALIA VIC

DISCUSSION PAPER AUGUST 2017

**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
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Above: Paul Wenn and Tony Walsh shared a life together for 25 years. Paul was diagnosed with Alzheimer's disease in his early 60s and later the diagnosis was confirmed as Lewy body disease. Paul died in 2014, 11 years after he was first diagnosed.
Photo: Cathy Greenblat

Front Cover: Mandy and Garry Lovell. Garry was diagnosed at age 47 with younger onset dementia and is now in residential care.

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Please note: names have been changed for the case studies

1 EXECUTIVE SUMMARY

Of the 413,000 Australians living with dementia, more than 25,000 are under the age of 65. A diagnosis of dementia at any age, brings a number of challenges. For those Australians under 65 years of age who are living with younger onset dementia, the experience can be particularly devastating. The issues related to a diagnosis at a young age, can be wide ranging and the effects are felt broadly amongst family and friends. Given the particular challenges of this cohort, it is essential that there are services available that are accessible, responsive and understand the needs of younger onset dementia.

For Alzheimer's Australia Vic, the peak body and charity for people, of all ages, living with all forms of dementia, our priority is to ensure people living with younger onset dementia and their families and carers, continue to have access to these services, in a way that best suits their needs.

For decades, people with younger onset dementia have fallen through the gaps between the disability and aged care sectors. Disability services do not have a good understanding of dementia or the specialist services required to support people with younger onset dementia. Aged care services are often out of reach due to age limits or their service delivery model is not appropriate for this group.

Recent sector reforms have seen a federal decision to split access to disability and aged services by an age distinction (with 65 years the defining age) allowing younger people with dementia, access to the National Disability Insurance Scheme (NDIS).

The introduction of the NDIS and its roll out over the last four years in Victoria has revolutionised the disability services sector with the aim to support a better life for Australians with a significant and permanent disability. This has brought positive change for a number of people living with younger onset dementia, however has left significant gaps in service.

NDIS plans focus on ensuring the person with a disability has choice and control over the services they access and whilst this has created opportunity for more flexible and age appropriate services for people living with younger onset dementia, it has not made any provisions for service availability to families and carers. Family members require access to a range of

education, information and support services to ensure they are able to provide long term care to their loved one and their own physical and mental health needs are met.

Specialised knowledge and education about younger onset dementia will also be vital for health professionals working in the disability sector. Experience demonstrates that this capacity building has been crucial in a sector that have previously focussed on other forms of disability and not typically developed any real experience of working with people with dementia. With targeted, person centred training, services are better equipped to meet the specific needs of people living with younger onset dementia and their families. These services are not funded by the NDIS, and after June 2018, without funding will cease to exist.

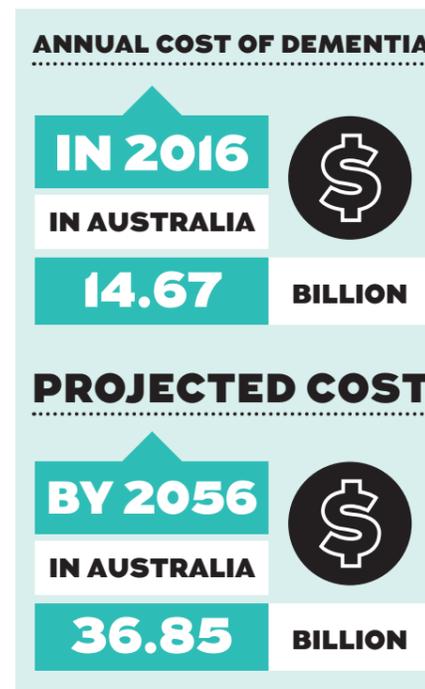
Alzheimer's Australia's Younger Onset Dementia Key Worker Program currently provides this highly experienced and specialised support through a client focused, holistic approach. Since its inception in July 2013 the program has supported more than 1,650 Victorians. Of these people, 75 per cent are family members and carers. The Younger Onset Dementia Key Workers have also been leaders in providing younger onset dementia education and training to thousands of health care providers who work with people with younger onset dementia and their families. This program is a critical initiative in meeting the needs of all people living with younger onset dementia, including families.



2 ALZHEIMER'S AUSTRALIA VIC

As Victoria's peak, non-profit body for people living with dementia, their families and carers, Alzheimer's Australia Vic works to prevent dementia, while valuing and supporting people of all ages living with the condition.

There are currently more than 104,000 people living with dementia in Victoria, with an annual national cost to the community in excess of \$14 billion (Alzheimer's Australia, 2017). Dementia is the second leading cause of death in Australia (Australian Bureau of Statistics, 2013). Yet, despite this high prevalence, understanding of the condition, both in the community and among health professionals, remains alarmingly low.



3 YOUNGER ONSET DEMENTIA

Younger onset dementia is the term used to describe the onset of symptoms of dementia before the age of 65. These people can be in their 50s, 40s and even 30s. There are more than 25,000 Australians with a diagnosis of younger onset dementia and this number is expected to nearly double by 2056.¹

Receiving a diagnosis of dementia at any age is challenging; however, being diagnosed in your 40s, 50s or 60s, a time at which a career and family are typically key priorities, can be particularly devastating for a person and their family and carers. The onset of dementia at this stage of life means the needs of this population differ significantly to the needs of those diagnosed at an older age. Most individuals will be employed, self-employed or in early retirement. They will have the usual mid-life social relationships and financial commitments. Some will have younger school aged children and be living with all of the normal challenges of raising children. Others will have young adult children, perhaps with their own families, while some will also be supporting elderly, frail aged parents. The additional challenge of dementia can be devastating to these individuals and their families.²

It is essential that there are services available that are of high quality, are easily accessible and are responsive and flexible to their particular needs.

¹ The National Centre for Social and Economic Modelling [NATSEM] for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016–2056*.

² Australian Institute of Health and Welfare (2012). *Dementia in Australia*; Alzheimer's Australia (2014). *Living with Dementia in the Community: Challenges and Opportunities*; Brooks D., Ross C., Beattie E. (2015). *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. Report for Alzheimer's Australia; Blay S. and Peluso E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163–71.

4 YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM

Alzheimer's Australia Vic has been working with people with dementia of all ages for over 30 years, identifying over this period that younger people with dementia, their families and carers have different issues and needs that require tailored supports.

Alzheimer's Australia Vic undertook a project in 2009 to ascertain the best model of support for younger people with dementia and their families. This resulted in the development of the Younger Onset Dementia Key Worker model, which was successfully launched as a federally funded national program in 2013. Since its inception, the Younger Onset Dementia Key Worker Program in Victoria has provided support to over 1,650 people living with younger onset dementia. The model is one that is client focused and holistic. Engaging all members of the family – and providing education, counselling and support to everyone impacted – ensures that the person with dementia is provided the best care possible.

This program has been a crucial element in the sustained provision of care and support for people impacted by younger onset dementia in Victoria. The program aims to improve the quality of life for people with younger onset dementia, as well as their families and carers, by providing them with a highly skilled point of contact with whom they can develop comprehensive strategies and optimise engagement with key support and care options. Currently the Younger Onset Dementia Key Worker Program is the only program in Victoria that provides individualised information and support aimed at improving the quality of life for people with younger onset dementia.

Funding for the Younger Onset Dementia Key Worker Program in Victoria allows Alzheimer's Australia Vic to provide key worker coverage throughout the state. A number of our staff are based in rural regions, providing opportunities for people living with dementia in country Victoria to access the same quality services available within metropolitan Melbourne. Further staff ensure services are available within Melbourne and two state wide specialist staff provide further service options. The program offers an integrated suite of services, delivered by a multidisciplinary team. Our Younger Onset Dementia Key Workers provide person-centred support at any point through the life span of someone with dementia. Our specialist Family Clinician provides counselling and support to families, in particular to

those who have children with a parent or grandparent with dementia. This role also provides ongoing consultative services to primary and secondary schools throughout the state. A complementary Care Consultant provides education and training to service providers across all disability, health and ageing sectors to ensure the services they offer are younger onset dementia-friendly. In addition to the one-to-one support provided to people with younger onset dementia and their families, a large number of innovative programs have been developed and are run by the team, further allowing flexible access to our service.

This model and our long history of working with people with younger onset dementia and their families allows us to provide a consistent and quality service. Feedback from our clients supports this approach, with many appreciating having one key contact person within the organisation and an ability to access a range of different supportive services from the one organisation.

5 NATIONAL DISABILITY INSURANCE SCHEME & MY AGED CARE

As Australia undergoes the radical transformation of both its disability and aged care sectors, the way in which younger people with dementia access services and supports has also changed. Traditionally, access to services was based on a disease diagnosis, with dementia categorised as an age-related illness: younger people with dementia therefore accessed services through the aged care sector. The experience for someone with younger onset dementia going through this process was frustrating, with many aged care services not understanding the disease distinction and turning younger people with dementia away due to their young age. Those that accepted younger people with dementia into their services only offered services more suitable to an older cohort.

Recent sector reforms however, have seen a federal decision to split disability and aged care services through an age-based distinction (with 65 years the defining age) rather than a disease-based distinction. This allows younger people with dementia access to the National Disability Insurance Scheme (NDIS). The implementation of the NDIS across the country has seen some positive outcomes for our younger clients with dementia; however younger people with dementia are still facing difficulty accessing appropriate services, and may even “fall between the gaps” of existing programs, including both the National Disability Insurance Scheme and My Aged Care.³ By 2018, the federal funding provided for the Younger Onset Dementia Key Worker Program will be re-directed into the NDIS.

The NDIS began its roll out in Victoria in 2013. Alzheimer’s Australia Vic embraced this as a positive change and has been assisting many of our clients to transition from aged care services to NDIS plans since that time. Because this interface with the NDIS is new, our clients, as well as the service providers with whom we work and the NDIS itself, have learned, adapted and evolved our mechanisms of engagement and support. Whilst there are still a number of challenges for people with a diagnosis of younger onset dementia, the depth and breadth of plans and services for clients has certainly improved over time. This is one of a number of

examples of the NDIS creating positive change for our younger clients with dementia. For those who had been accessing aged care services, the change has meant an increase in services offered and more flexible and age appropriate options. Being in control of the choices around their care has been empowering for our younger clients. Many have been able to think differently about the sorts of activities and supports they can access and are no longer tied to a package of services offered by the aged care sector that are limited and do not meet their unique needs.

The bulk of the work that Alzheimer’s Australia Vic’s Younger Onset Dementia Key Workers are funded to provide through the NDIS is “Co-ordination of Supports”. This involves being the key contact person in assisting a person with younger onset dementia to implement their NDIS plan and provide ongoing information, resource and supports. The NDIS focuses on placing the care recipient/ participant at the centre of the service system: and whilst this has indeed resulted in increased choice and control for people with younger onset dementia, it also presents a number of challenges for individuals and their families and carers. These include losing the benefits of a “whole-of-family” focus by reducing engagement with, and support for, families and carers. There are a range of services necessary for families and carers impacted by dementia, however the NDIS make minimal provision for any of these.

³ Alzheimer’s Australia (2017). Submission to Inquiry into the delivery of outcomes under the National Disability Strategy 2010–2020 to build inclusive and accessible communities.

CASE STUDY JESSICA

Jessica, a 56 year old woman with dementia – previously very active in her career – had become increasingly isolated, without access to supports; leading to declining health and wellbeing. A previous aged care package had been providing access to one day per week of respite at an aged care service with older people with dementia and two hours per week of home help for cleaning. Her husband was employed full time, with a need to maintain this employment due to financial commitments. With our support, the transition to an NDIS plan was enacted with service support engaged, five days per week. This includes three days per week for community access; in particular attendance at the gym for an exercise program, attendance at a walking group with people of similar age and planned activity group access with other people with younger onset dementia. As Jessica is no longer driving, transportation costs are also covered. Other days are used to support her to do grocery shopping and meal preparation for the family. This support has greatly enhanced her quality of life, increasing her access to health and fitness programs as well as meaningful activity in the home. The support also provides social companionship, which was identified as a significant loss related to her career ending.

6 WHO SERVICES FAMILIES AND CARERS?

Our experience has demonstrated that people living with dementia have an improved quality of life, better health and wellbeing, and an ability to live at home within the community for longer when their carers and families are educated, supported and engaged within the service sector. Whilst the Younger Onset Dementia Key Worker Program provides quality services for people with younger onset dementia, around 75 per cent of the supports and services provided through our program are taken up by carers and family members. This work includes access to tailored education and information sessions, counselling services for families (including children) and friends, delivery of specialist carer support groups, psychoeducational group programs and peer to peer support opportunities.

These services are not funded by the NDIS and after June 2018, without funding, they will cease to exist.

We know that support for families and carers reduces carer stress, reduces the physical and mental health impacts on the carer and their family, and reduces social and lifestyle impacts that have, in the past, resulted in school drop-outs, family and marriage breakdowns and social isolation.⁴ Poorer health and wellbeing outcomes for both carers and people with younger onset dementia will place increased burden on

our community and public health systems. It will also lead to premature placement of younger people with dementia into residential aged care services.⁵

Services for carers and families are a vital element in every family's journey with dementia. However, the reforms to both the disability and aged care sector make it more challenging for families to receive the supports they need, or for their services to be delivered in conjunction with those of the person living with dementia.

YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM

75%

OF THOSE ACCESSING
THE PROGRAM ARE
CARERS AND FAMILY

4 Brown, J., Sait, K., Meltzer, A., Fisher, K. R., Thompson, D., Faine, R. (2012). *Service and Support Requirements of People with Younger Onset Dementia and their Families*, for NSW Department of Family and Community Services, Ageing, Disability, and Home Care, Sydney.

5 Alzheimer's Australia 2013. *Quality of Residential Aged Care: The consumer perspective*. Retrieved from: https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

7 WHO PROVIDES SUPPORT FOR PEOPLE BEFORE NDIS ELIGIBILITY IS ASSESSED?

Although there are challenges for people living with younger onset dementia in receiving appropriate services under the NDIS, the barriers to service extend even before their assessment. Many clients have experienced difficulties in access to, and appropriate planning with, the NDIS. Without Alzheimer's Australia Vic's supports throughout this pre-planning process, eligibility for many clients is limited and plan creation is inappropriate for the needs of a younger person with dementia.

People with younger onset dementia have expressed a need for early intervention support services such as community participation and engagement, family and relationships support, emotional and wellbeing support, respite support, as well as financial, legal and employment support. While these services are essential, our experience with the NDIS has been that immediately following diagnosis a number of our clients with younger onset dementia have been unable to access the NDIS because their disability is not significant enough at the early stages of the disease. For people with a progressively deteriorating neurological disorder, like dementia, this is a crucial time for education, to be planning for the future by ensuring supports are in place and access to community and health organisations is available. Without pre-planning support, younger people with dementia and their families will not have access to services through any sector and their likely future outcomes worsen as a result.

For those of our clients who are deemed eligible, an average of 15–20 hours is required to support them through the application and pre-planning phase. This is a lengthy and complex process that is unfunded by the NDIS, despite the enormous need for clients with cognitive issues and complex needs to access this service to prepare them adequately for the NDIS. Alzheimer's Australia Vic spends a significant amount of time assisting clients to apply to NDIS, assisting them to complete paperwork, explaining the NDIS and how it operates, preparing people for planning meetings, assisting them to identify the types of services they need at present and into the future, and being a liaison between the person with dementia and the NDIS.

CASE STUDY JANE

A recent success story involved Jane, a young woman with a diagnosis of a rapidly progressing frontotemporal dementia living in a region that will not roll into the NDIS until 2019. Due to her declining health and critical needs, Jane was granted early access to an NDIS plan which will allow continued supports in the home, delaying entry into residential aged care. This would not have been possible without the advocacy and support from our Younger Onset Dementia Key Worker.

Our Younger Onset Dementia Key Worker Program has the experience of working with younger people with dementia and their families and understanding of the needs individuals have throughout their dementia progression. Given the disability sector has not had previous experience of people living with dementia, our support for clients is essential in ensuring access to the NDIS and that plans include services vital to increasing their quality of life. Without alternative or modified funding models, this pre-planning support will not be funded into the future, increasing the chances that younger people with dementia will continue to fall through the gaps without access to crucial services.

8 SERVICE SECTOR CAPACITY BUILDING

If the funding currently allocated to the Younger Onset Dementia Key Worker Program is re-directed into the NDIS in 2018, a further impact of this transition will be the loss of capacity building within the disability sector. In our experience this service has been crucial for a sector that focuses on other forms disability and has not typically developed any real experience in working with younger people with dementia.

Clients report to us that the vast majority of new services being offered have no experience or skill in working with people with dementia. Staff at these organisations are not aware of the changing needs of someone with dementia and do not understand the cognitive challenges faced by this cohort. Reports from disability staff we have worked with confirm this picture and they say that, given their inexperience, they lack confidence in delivering services to meet the particular needs and issues of younger people with dementia and their families. Alzheimer's Australia Vic is well placed to meet this need and we already provide this education and training as well as tailoring it to the individual needs of the client and the service provider.

Through our Younger Onset Dementia Key Worker Program, Alzheimer's Australia Vic also provides education and training to service providers within the community, acute and residential aged care sectors, ensuring that knowledge and understanding of the particular issues and needs of people with younger onset dementia also informs this sector. This is vital given people with younger onset dementia often still end up in the aged care sector, especially when residential care is required. Broad aged care sector training programs do not otherwise provide the level of education that organisations need to feel confident in working with people with younger onset dementia.

With targeted person-centred training, we have found organisations to be more flexible in their provision of services and staff feel assured in their abilities to deliver age appropriate services.

9 RESPITE AND RESIDENTIAL AGED CARE

A particularly important element to the capacity building work undertaken by Alzheimer's Australia Vic is our work with residential aged care facilities.

There are varying estimates as to the likelihood of admission into residential aged care for a person with dementia. However, approximately 60–90 per cent of people will enter a residential aged care facility when they reach a point where they require ongoing high-level support.⁶

For our younger clients with dementia, despite access to the NDIS, this is still a stark reality.

The NDIS does not provide appropriate respite and residential care options for our younger clients, particularly those at late stage requiring higher levels of care than the disability sector is able to offer. As such, younger people with dementia are still straddling two systems and will need to access this part of their care through the aged care sector. With the changes to this sector, accessing any of these services has become more difficult, due to the strict guidelines enforced around a person's age. Without our support and advocacy in this space, individuals with dementia and their family members are facing delays in this process and are not able to be adequately serviced through this time with an NDIS plan.

Unfortunately, for the majority of younger people with dementia, the move into a residential aged care facility is inevitable and the transition is made smoother if the person has access to short term respite stays in that same facility beforehand. This staged, supported transition allows the person with dementia to develop familiarity and become more comfortable; it also gives our service a chance to provide education, training and support to staff ensuring the placement is a success.

Placement breakdown in aged care facilities for younger people with dementia often results in lengthy hospital admissions whilst appropriate care can be sourced.

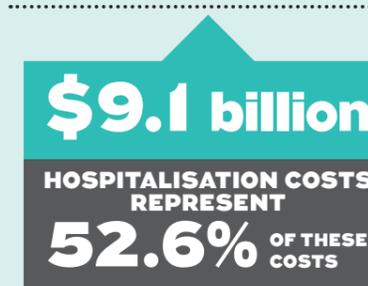
The total annual direct cost of dementia in 2017 is estimated to be \$9.1 billion dollars, with the costs of hospitalisation representing 52.6 per cent of this figure.⁷ Without specialist dementia services the economic demands coming from this cohort will likely increase.

Despite having an NDIS plan, the type and level of support delivered in this case by Alzheimer's Australia Vic was not funded through this system, further demonstrating the need for highly specialised, disease specific services. Alzheimer's Australia Vic is concerned that other families in these situations will not have access to this type of support in the future, with devastating outcomes for the person with dementia and surrounding family members.

RESIDENTIAL CARE PLACEMENT BREAKDOWNS



DIRECT ANNUAL COST OF DEMENTIA IN 2017



⁶ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

⁷ The National Centre for Social and Economic Modelling [NATSEM] for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016–2056*.

CASE STUDY SAM

Sam is a 45 year old man with a dementia diagnosis, recently referred to our service. Prior to referral to Alzheimer's Australia Vic, this man had entered four residential aged care facilities. Due to his young age, physically fit nature and challenging symptoms, these previous aged care facilities had not managed appropriately and placement broke down.

Our service was able to meet with the family and gather information about their specific needs and issues. Identification of a new facility was undertaken and focussed education and training delivered to the staff. This has

supported the staff to provide age appropriate stimulation and care within Sam's living environment, leading to a positive placement experience for this family and a reduction in many of the previous challenging symptoms from this man.

Through the development of the relationship with this family, our Younger Onset Dementia Key Worker Program has also provided other specialised services to both his wife and teenage children, better equipping them to understand dementia and provide supports to their husband and father and to each other.

10 CONCLUSION

For decades, people with younger onset dementia have fallen through the gaps between the disability and aged care sectors. Disability services do not have a good understanding of dementia or the specialist services required to support people with younger onset dementia. Aged care services are often out of reach due to age limits or their service delivery model is not appropriate for this group.

The introduction of the NDIS for younger people with dementia has brought positive outcomes; it has however left a number of gaps in services, most significantly the provision of services for families and carers.

There is precedent for the provision of effective person-centred support for people with younger onset dementia and their families. The Alzheimer's Australia Vic Younger Onset Dementia Key Worker Program provides a highly experienced and specialised service. This program is a critical initiative in meeting the needs of all people living with younger onset dementia, including families.

As funding for the Younger Onset Dementia Key Worker Program transitions to the NDIS, it is essential that consideration is given to how to continue to provide this important specialist service. Mainstream, non-condition specific services will struggle to effectively meet the needs of people with younger onset dementia and the lack of provision to families and carers will lead to devastating outcomes.

A diagnosis of dementia at a young age is an overwhelming and confronting experience. It is essential that there continue to be services available that are high quality and specialised, easily accessible and responsive to the unique needs of this cohort.

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