

NATIONAL CONSUMER SUMMIT

19 - 20 MARCH 2013

YOUNGER ONSET DEMENTIA: A NEW HORIZON?

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“At first I hid and I didn’t want to come out, but then I did and I found that people accepted me...they knew I was different but they also knew I had lived in the community for many years....we have to do something to improve people’s understanding of younger onset dementia so they know it just doesn’t happen to people who are older”

There are 24,000 people with younger onset dementia in Australia. Yet, access to appropriate care and support is extremely limited.

Alzheimer’s Australia, with the support of Nich and Rosemary Rogers, the Lord Mayor’s Charitable Foundation and the Commonwealth Government, held a National Summit on 19-20 March 2013 to examine the issues facing individuals with younger onset dementia, determine current gaps in responses and develop recommendations for the way forward in order to improve the quality of life for people with younger onset dementia and their families.

This Report provides a summary of the Summit and describes the actions required to develop better responses to the needs of people with younger onset dementia, their carers and their families.

This Summit is particularly timely as Australia is on the brink of fundamental reform in both the disabilities and aged care sectors. The National Disability Insurance Scheme (NDIS) will provide resources and personalised care plans for individuals with younger onset dementia. Funding through the Tackling Dementia package which is part of the ***Living Longer. Living Better.*** aged care reforms will support a national network of Younger Onset Dementia Key Workers through Alzheimer’s Australia.

A new horizon has opened up for younger people with dementia and their families and in the words of the participants at the 2009 Summit “It’s all about HOPE – Helping Other Possibilities to Emerge”.

At the time of the Summit in 2009 the NDIS was not even on the political agenda and aged care reform was far from certain. Clearly in 2013 we are facing new possibilities for change, but with this comes the challenge of ensuring that the reforms are implemented in a way that results in better quality of life for people with younger onset dementia and their families.

Younger Onset Dementia

Younger onset dementia is a term used to describe any form of dementia that has an onset of symptoms before the age of 65. The Australian Institute of Health and Welfare have estimated that younger onset dementia affects around 24,000 people in Australia in 2013.

There is a lack of awareness and understanding, even among health professionals, that dementia can develop at any age. As a result people with younger onset dementia are often misdiagnosed and face even longer delays in getting a diagnosis of dementia.

Even when a diagnosis is made, there are few services that are designed to provide appropriate care and social support for younger people and their carers. Individuals with younger onset dementia face a unique set of challenges with changing financial circumstances, limited access to appropriate services, new social challenges and often too frequently fundamental changes to their relationships with family and friends.

Priority Areas

Participants at the Summit identified the need for priority action in six areas:

1. Increased awareness to reduce stigma and to improve the opportunity for social participation by individuals in their local community.
2. Timely and accurate diagnosis with access specialist services as needed.
3. A National Disability Insurance Scheme that places the person with younger onset dementia and their families at the centre and supports their choice and control over their future and the services and supports they require.
4. Action by service providers to redesign their services so they can respond flexibly to the goals, aspiration and plans of younger people with dementia.
5. Opportunities to participate in society with access to employment and adequate income security.
6. There need to be a greater investment in research into cause, cure and care of younger onset dementia if there is to be a better understanding of the condition.

Awareness

“Too often I find that I am telling people about my dementia and all they are concerned about is figuring out if they have it too – rather than understanding what is happening to me...”

Most Australians are not aware that dementia can affect people at any age. As a result, people with younger onset dementia often face stigma, discrimination and in some cases disbelief about their condition.

The condition can have a devastating impact for the person with younger onset dementia, their family, children and friends. Relationships with loved ones change from partners to carers and people with young families often find it difficult to access services to help their family transition, such as counselling for young children.

In order to protect the human rights and dignity of younger people with dementia and improve their quality of life, there must be a better understanding in Australian society of the condition and its impact on the lives of thousands of Australians. We must change community attitudes from one of avoidance to inclusion.

It is also important to recognise the impact of different cultural perceptions on understanding and coping with dementia, especially in relation to personal or community stigmas. Similarly, there is a need to recognise the particular problems of those who live in regional and remote Australia.

If we are to achieve an Australian society that better understands the needs of people with younger onset dementia and supports them to participate fully in society it is recommended that:

1. The Australian Government fund a national awareness program through Alzheimer’s Australia focusing specifically on younger onset dementia and involving younger people with dementia in telling their stories.
2. Alzheimer’s Australia establish a national advisory group of people with dementia of all ages to advocate on behalf of people with dementia and in particular to contribute to shaping a national awareness program, evaluating the work of the Younger Onset Dementia Key Workers, and raising the profile of people with younger onset dementia in this NDIS.

Timely and Accurate Assessment and Diagnosis

“I knew there was something wrong, my wife knew there was something wrong....but the doctors did not. It was only through my wife’s perseverance that I was able to be diagnosed – 12 months after I first sought help...by that time my life had fundamentally changed”

On average, it takes approximately three years after first noticing symptoms of dementia until obtaining a formal diagnosis of dementia. This is time that people with younger onset dementia can ill afford.

For younger people the time taken can be much longer because of the lack of awareness among many medical professions of younger onset dementia and because many younger people may have rarer forms of dementia which will necessitate the involvement of different specialists.

Often as the first port of call, General Practitioners are ill equipped to recognise the symptoms of dementia they are presented with by younger people with early onset dementia. Frequently individuals with younger onset dementia receive incorrect diagnoses of depression or other mental health concerns before receiving an accurate diagnosis of dementia.

These delays are traumatic in the lives of younger people and their families. Individuals are aware that something is wrong but are uncertain about what it could be. Some face difficulties in employment or in their relationships due to their unexplained symptoms. Delays in receiving an accurate diagnosis are compounded by limited access to specialist services in many parts of Australia.

There is a widespread lack of awareness regarding the availability of genetic testing and no national framework for genetic testing for younger onset dementia. Access to testing and the cost of testing is both variable and expensive. Most genetic tests are not listed on the Medical Benefits Scheme.

It is recommended that:

1. Within the National Dementia Action Framework priority should be given achieving the timely and accurate assessment of younger onset dementia.
2. The funding contained in ***Living Longer. Living Better.*** to achieve timely diagnosis should also include younger onset dementia in the development of training programs for general practitioners and other health professionals.

3. The work being done by the Minister's Dementia Advisory Group and the Department of Health and Ageing on primary care and dementia should ensure that the availability of medical benefit items identified for the assessment for people with dementia are inclusive of those with younger onset dementia.

National Disability Insurance Scheme and Younger Onset Dementia Key Workers

“It’s an alien landscape and I don’t understand how it all works....I needed someone to help me navigate through this new world”

Summit participants welcomed the principles on which the National Disability Insurance Scheme (NDIS) is founded. Summit participants understand these principles to be:

- Funding based on assessed need.
- A life long approach to providing care and support which means that assessment will look beyond immediate need.
- A focus on early intervention.
- Choice for people with a disability and their family and carers which puts them in control of the care and support they need.
- Safe guards that support people in exercising this choice and to help them make informed choices.
- A focus on ensuring people maintain to the maximum extent possible their independence and full potential.
- Nurture and sustain families, carers and friendship groups that are critical to improving the lives of people with a disability.
- Comprehensive information and referral services to help people with a disability.

When put into action, these principles will provide HOPE. That is care and support designed so that the individual and their family are at centre of how services are organised and delivered in response to their unique circumstances.

In recognition of the importance of community participation and social engagement for people with early onset dementia – under the NDIS a greater focus will be placed on responses that enable individuals to participate in their local communities in ways that enhance their quality of life and provide opportunities for many individuals with younger onset dementia to contribute as they still want to do.

The Summit participants applauded the funding provided in ***Living Longer. Living Better.*** for the employment of Younger Onset Dementia Key Workers through Alzheimer’s Australia. For all people with dementia, it has long been a dream to have one on one support from a person who can provide advice and support on a continuing basis to assist in finding a pathway through the maze of care, support and health services.

These workers will act as an expert single point of access for people with younger onset dementia. They will identify service gaps, assist in developing services and most importantly advocate and work with people with younger onset dementia and their family carers.

Summit participants agreed that a new National Consumer Dementia Advisory Committee should have a role in evaluating these key workers and helping to shape their role over the next three years.

It is recommended that:

1. People with younger onset dementia and their family carers take the opportunity to access services through the NDIS launch sites in Barwon and Hunter regions in Victoria and New South Wales.
2. Examples of individual service plans be developed to demonstrate the potential of the NDIS to respond to the needs of individuals with younger onset dementia.
3. That as part of the planning process to support the NDIS recognition is given to the importance of creating social connections and opportunities for community participation in achieving improved outcomes for people with younger onset dementia
4. The Consumer Dementia Advisory Committee works with Alzheimer’s Australia to refine and evaluate the Younger Onset Dementia Key Worker program with a view to extending the program to support all people living with dementia.

Redesign of services

“One size does not fit all – the needs of people with younger onset dementia are different from others who have dementia.”

There are currently around 2,000 people in residential care who are under 65 and many individuals with younger onset dementia accessing community and respite services targeted at frail aged Australians.

Staff are often unaware of the differing needs of someone with younger onset dementia as they lack appropriate training. Summit participants recognised that for individual service plans to work, there has to be flexible and appropriate services available. Fundamentally there needs to be recognition of the differing needs of people with younger onset dementia – they are not the same as people who are frail and aged with dementia.

There is need for age appropriate services for people with younger onset dementia. Such services should recognise, for as long as is possible, that the control and choice of services to be provided should remain in the hands of the individual and their family and tailored to their individual circumstance.

For individualised services more flexible responses will be required to the provision of community services, respite, residential care, social support and engagement, and employment opportunities, which previously have not been accessible for people with younger onset dementia.

Service developments also need to ensure there are clear, timely and appropriate links to carer support and services to assist them to continue in their caring role. This needs to include the availability of planned and managed respite that not only provides respite for the carer but also provides appropriate and meaningful activities and social interaction for the person with younger onset dementia.

It is recommended that:

1. Alzheimer's Australia and the Younger Onset Dementia Key Workers work with services providers to establish, expand and develop flexible and age appropriate community, respite and residential care services.
2. Alzheimer's Australia and the Consumer Dementia Advisory Committee continue to organise forums that promote dialogue between those with younger onset dementia and service providers with a view to promoting a better understanding of the social and care needs.
3. A training program is developed for the disability sector to up skill workers on the specific needs of people with younger onset dementia.

Participation

“I could no longer work – I lost my job...that was devastating for me and for my family. We had not planned for me to have dementia – I thought I had many years before I would stop working....”

Summit participants recognised that an important element of NDIS is to promote social inclusion through the participation of people with disabilities in the wider community. This is essential both to an individual’s self respect and recognition in the wider society of the value and worth of people with disabilities. This approach is important for people with younger onset dementia who face difficult issues with regards to employment, discrimination and social isolation.

Strategies that promote the independence and rights of younger people with dementia through employment opportunities and opportunities for social engagement are needed.

A supportive income security system is needed that recognises the potential impacts of developing younger onset dementia including; loss of individual or joint income, loss of superannuation and restrictions to accessing accumulated funds early, loss of income protection insurance and the inconsistencies between access to disability pensions and the financial impacts of accessing non-subsidised long term care.

It is recommended that:

1. The Consumer Dementia Advisory Committee discuss the issues that face people with younger onset dementia and their families in accessing appropriate income support and advocate for necessary changes to Centrelink and the Minister for Families, Housing, Community Services and Indigenous Affairs.
2. Strategies are developed to support people with younger onset dementia maintain their current employment or find alternative employment options that give them a purpose in life they may be looking for.
3. Care and support services are developed and promoted that recognise the importance of social engagement for people with younger onset dementia.

Dementia Research

Summit participants recognised that there needs to be a much greater investment in dementia research into care, cause and cure if there is to be a better understanding of younger onset dementia and the best approach to supporting people with younger onset dementia.

There is a need for more research into disorders that affect predominantly younger people such as frontal temporal, lobar degeneration and the rarer forms of dementia.

In developing the research agenda for people with younger onset dementia in addition to a focus on cause and cure – there is need for translation research to strengthen our collective understanding of what support services and interventions work for this group.

It is recommended that:

1. Within the \$200m over five years that Alzheimer's Australia is seeking for dementia research in the 2013 Federal Budget there should be a focus on research that will promote a better understanding of younger onset dementia and the models of care that may be most appropriate.

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The Summit participants would like to thank the His Excellency the Honourable Governor of Victoria, Alex Chernov AC QC and Mrs Elizabeth Chernov for the hospitality provided to Summit participants. It was a wonderful opportunity to reflect on the outcomes of such an important day.

Lastly the Summit participants would like to thank all the staff at Alzheimer's Australia and Alzheimer's Australia Vic who worked to make this Summit possible and to start the process of engagement with the NDIS Agency and the government departments involved in the policy work around NDIS.