

A call to action from Younger Onset Dementia Summit

Younger Onset Dementia Summit

Melbourne Convention Centre

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Thank you Maree for your generous introduction, and Ita, for a wonderful opening speech, and for your commitment and passion for our cause. And what a wonderful start to our proceedings to hear from Chontell, Edie and Tony; thank you for sharing your deeply personal stories. My heart was nodding at many of their stories.

It is my great privilege to be speaking to you today to represent the participants of the 2013 younger onset dementia Summit. I hope to provide a summary of the outcomes and describe the actions required to develop better responses to the needs of people with younger onset dementia, our carers and our families.

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.

I am one of them.

Hearing Chontell's story brought tears to my eyes as it gave me a frightening glimpse of what my sons are probably experiencing.

Diagnosed aged 49, I was working full time, studying a double degree, and raising two teenage boys with my husband. I quickly discovered that access to appropriate care and support is extremely limited.

We are speaking out because there has been a gross under representation of people with dementia deciding on our care and futures, and the only way you can understand us is to hear our stories. As with every other group in society, there should be **nothing about us without us**.

We are also speaking out because much of our care feels symptom based, and nothing will change until we recognise it is imperative we all understand the human cost of dementia. We are mothers, fathers, lovers, daughters, wives or husbands, employees or employers, grandmothers, aunties... it is a tragedy so many just see our deficits.

The summit in 2009 began the process of self advocacy and change, and we hope this summit will take it to another level.

Why do we need reform?

It is hard to see reform is needed if what you have always done is easy, and no-one tells you it needs to be changed. The service sectors have traditionally cared for the elderly or the intellectually or physically disabled, rather than PWYOD, and we are in a unique position to evaluate the systems and services, as we are more likely to seek diagnosis earlier, and are more likely to speak up.

Dementia is not the most feared disease for us, and in fact most of us didn't even suspect we might have it! The next onslaught of people with dementia, younger and older onset, are the baby boomers, who historically have not been ones to sit back and just accept perceived injustices, or have their decisions made for them. Wanting change is not done to discredit current services. We speak up as advocates for ourselves and educators to service providers and the wider community. Through the power of personal stories we hope to help you see the need for, and help bring about reform.

Priority Areas

Yesterday the participants at this 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.

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. My husband said to me recently, “I know I am losing you, and I am afraid of what the future holds.”

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.

Yesterday you would have had difficulty picking who of us has a diagnosis of dementia; we are young, fit, active individuals.

2. Timely and accurate diagnosis with access specialist services as needed.

As previously mentioned, 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.

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.

Summit participants welcomed the principles on which the National Disability Insurance Scheme (NDIS) is founded.

These principles will ensure that care and support is designed so that the individual and their family are at the 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 younger 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 recently announced Younger Onset Dementia Key Workers will act as an expert single point of access for people with younger onset dementia. They will identify service gaps and assist in developing services. Most importantly they will advocate and work with people with younger onset dementia and their family carers.

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.

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 have 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.

Service developments also need to ensure there are clear, timely and that appropriate links to carer support and services are available to assist individuals 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.

5. Opportunities to participate in society with access to employment and adequate income security.

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

A supportive income security system is needed, that recognises the potential impacts of developing younger onset dementia on a person's financial situation. Rules around access to superannuation and income security need to better reflect the unique needs of people with younger onset dementia and their families.

6. There needs 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.

Summit participants recognised that there needs to be a much greater investment in dementia research.

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.

Thank you

I'm a glass half full kind of person, and try to stay positive. I often say, "We live until we die" so it is important to spend my energy on living as well as I possibly can, in spite of this hideous disease.

I would like to thank everyone who participated in the summit yesterday and those attending today, particularly those with younger onset dementia and their carers, and I look forward to seeing the outcomes of this summit becoming a reality for all of us here today.