

Dementia not recognised as a disability

Younger Onset Dementia Summit

Melbourne Convention Centre

March 19, 2013

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Good morning, I'm Glenda Parkin from Perth. My topic is: dementia not recognised as a disability.

I stand here today and tell you that I have a disability. Many people say I look just fine, but that's only on the outside. I am sure that many of you will relate to this situation. I was diagnosed 3 years ago at aged 56 with early onset of the visual variant of Alzheimer's, called Benson's Disease. It's a relatively rare form of dementia, but nonetheless it has equally disabling consequences over time.

After my diagnosis I had to resign my job as the Principal of one of Perth's leading girls' boarding schools. Prior to this I was a teacher and a university lecturer. I have university qualifications including a PhD. But now my ability to read even this speech is compromised by the disease. I don't see things that are there, and I see things that are not there, and I can only read very slowly.

For this reason I am going to ask my husband and carer to read a part of this talk to save time. As yet I haven't needed dementia specific services, but I've met with others who have used them, but they literally cannot speak for themselves because of their disability.

Their stories highlight situations where they have experienced discrimination and other issues that people over the age of 65 with dementia don't experience.

Our first example is a man who was diagnosed with Fronto-temporal Dementia at age 53. To financially support his family and meet the costs of his care, his wife returned to work after he gave up his nursing career. He received assistance from the Western Australian Government-funded HACC services, and from the Commonwealth-funded Extended Aged Care at Home Dementia package. This provides him with social support and transitional care for a limited number of hours each week while his wife works.

However, because he is under 65, he isn't eligible for any supplementary assistance from the Commonwealth's Consumer-Directed Respite Care package. He receives a Commonwealth Disability Support Pension and his wife receives a carer's allowance,

but they are means-tested, and therein lies the double bind for them: he loses his job, and income, due to his disease, while his wife returns to work to provide an income for the family and to meet the costs of his care, but they are penalized by the means test because of her income. Furthermore, unlike pensioners with or without disability over the age of 65, his frequent ambulance transfers to hospital are not provided freely, or at concessional rates, unless in an emergency. And now, at the point of needing full-time residential high care while still under 65, he has met with further financial discrimination. Unlike others in high care over 65 with a disability, including dementia, he was asked to pay an accommodation bond, and, when told what the bond amount would be, no recognition was made of his fore-shortened career, the impact that had on his family circumstances, debt levels and reduced time to accumulate life savings.

Our second example is a man, also with Fronto-temporal Dementia, diagnosed at age 52. He was asked to resign from his public sector job. His wife returned to work to maintain an income for their family and to meet the cost of his care. This couple has experienced the same issues as the first couple. However, he has an issue with accessing his superannuation. He was declared totally and permanently disabled, which gave him the full superannuation amount, but he wasn't able to access the so-called insured component of his super to help with his care. Also, he pays tax on any withdrawals that he is allowed to make because he is under 60.

In this presentation we have focused on the employment and financial issues faced by those with younger onset dementia. There are many other issues where younger onset dementia is not recognized as a disability.

These include issues with public transport, customer service and even reliance on our carers. There is so much more that I could tell you but I would be here all day. Ultimately, dementia needs to be recognized as a disability by the Government and society. In conclusion, these issues and areas of discrimination show that a 'one size fits all' approach won't always work for people with younger onset dementia.

Policies on access to services, funding, and bureaucratic process, need to change, and change quickly. Some of these matters are central to the Government's

proposed National Disability Insurance Scheme. I hope they are resolved in time for the people we have mentioned, and by the time that I, too, will need assistance.

Thank you for listening to me.