

Media Release

ONLY 35? YOU'RE *NOT* TOO YOUNG FOR DEMENTIA

The needs of people with younger onset dementia and their families will be the focus of a national summit to be held in Canberra on 23 – 24 February 2009.

The Younger Onset Dementia Summit is being organised by Alzheimer's Australia - the national peak body for people with dementia and their families - and the Parliamentary Friends of Dementia, co-convened by Sharon Grierson MP and Senator Marise Payne. It has been funded by the Australian Government and will be attended by 70 people from every State and Territory.

Participants will have the opportunity to talk with a number of politicians during the Summit. In addition, a reception for participants will be held on the evening of Sunday 22 February 2009 at Government House attended by Her Excellency, the Governor General of Australia, and Mr Michael Bryce, AM, AE.

The Summit will present its findings and a series of recommendations to the Hon. Justine Elliot, Minister for Ageing, following two days of in-depth discussion and sharing of experiences.

Glenn Rees, the National Executive Director of Alzheimer's Australia, said, "For the 10,000 Australians under 65 years of age who have younger onset dementia, it is critical that policy makers and the wider community understand that life can never be the same after a diagnosis with dementia.

"The reaction of doctors, health professionals, family and friends to younger people with concerns about dementia was often that 'you're too young for dementia' because Australians associate the condition with older people.

"The objective of the Summit is to draw attention to the special needs of people with younger onset dementia and their families. These include delays in diagnosis, access to services and employment and financial issues.

"Although a diagnosis of dementia is profoundly life-changing, it is also important to know that much that can be done to assist the younger person and their families and carers," said Mr Rees.

"For example, access to credible information and education, backed up by well designed support services and respite care, will help to ensure that younger people are able to engage in their lifelong activities for as long as possible. They also present an opportunity for families to plan and implement strategies to cope with the changes that come over time following a diagnosis of dementia.

“In preparation for the Summit, there have been consultations with consumers around Australia. Among the key issues identified for discussion are increased awareness of younger onset dementia in order to reduce stigma and social isolation; access to appropriate services that meet the needs of younger people; employment and financial support and steps to make legal and administrative systems more user-friendly and responsive to their particular circumstances.”

The personal stories of many of the attendees are also included in a new publication, which is being released to coincide with the Summit.

Mr Rees said, “Insights into the stories of those who live with younger onset dementia are in a new Alzheimer's Australia publication ‘*In our own words*’. These stories tell of the trauma in hearing the diagnosis of dementia and the heartbreaking uncertainty that can exist for many years before the condition is accurately diagnosed.”

The publication is available at www.alzheimers.org.au/youngeronsetedementia.

Mr Rees concluded, “Clearly a person in their 40s or 50s, who may still have children living at home or mortgage repayments stretching well into the future, faces very different issues to an older person who develops dementia. Regardless, each person has the right to community understanding and access to appropriate kinds of support to ensure they can continue to engage and participate in society for as long as possible.

“This Summit is an opportunity for the community, service providers and policy makers to think differently about dementia and to ensure the social inclusion of a small but growing group of individuals and their families who have been largely hidden or gone unrecognised until now.

Photo Opportunities:

- **Government House, Canberra – 5 – 6pm, Sunday 22 February:** Reception for Summit participants attended by Her Excellency, the Governor General, Ms Quintin Bryce AC
- **Rydges Lakeside, Canberra – 9am, Monday 23 February:** Opening of the Summit by the Hon. Justine Elliot, Minister for Ageing
- **Mural Hall, Parliament House, Canberra – 12.50 – 1.15pm, Tuesday 24 February:** Presentation of Summit Communiqué to members of the Government and Opposition, and Parliamentary Friends of Dementia

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