



Alzheimer's
Australia
Living with dementia



National Consumer Summit Younger Onset Dementia *Not too young for dementia*

“It’s all about HOPE –
Helping Other
Possibilities to Emerge”

Summit participants

Communiqué
Canberra 23-24 Feb 2009

Dementia strikes at any age. It profoundly affects the quality of life for thousands of younger Australians every day.

This communiqué and supporting recommendations address how the quality of life can be maintained and improved for people with younger onset dementia, their families and carers.

The Summit

More than 100 people attended the Summit.

The Summit involved primarily people with younger onset dementia, carers from all States and Territories and also key partners¹ working with people with younger onset dementia.

Summit participants call on the Australian Government to recognise the needs of people living with younger onset dementia by providing dedicated funding for services that meet their unique needs.

Younger onset dementia

Younger onset dementia is the term used to describe any form of dementia with onset of symptoms in people under the age of 65. It is estimated that younger onset dementia affects approximately 10,000 people in Australia today.

The needs of this group are special because there is low awareness, even among health professionals, that younger people may have dementia. Due to this, there is poor access to services that provide care and social support for younger people and their carers and the condition can have a devastating impact on the person with younger onset dementia, their family, their children and their friends. People have a right to tailored dementia services regardless of age.

¹Alzheimer's Australia invited AIDS Dementia and HIV Psychiatry Service, Alcohol Related Brain Injury Australian Services (ARBIAS), Down Syndrome NSW, Huntington's Disease Australia, National Stroke Foundation, Motor Neurone Disease Australia, Multiple Sclerosis Australia – ACT/NSW/Vic, Parkinson's Australia and Young People in Nursing Homes National Alliance to the Summit.



Priority Areas

Participants at the Summit identified six priority areas that require action:

- 1 Increased awareness to reduce stigma and social isolation.
- 2 Timely and accurate diagnosis.
- 3 Access to appropriate services.
- 4 Employment and financial needs.
- 5 Legal and bureaucratic issues.
- 6 Increased investment in research.

A partnership approach

Complementing these priorities, the partners endorsed the building of closer collaborative links between Alzheimer's Australia and groups concerned with Down Syndrome, Motor Neurone disease, HIV/AIDS, Parkinson's disease, Huntington's disease, Multiple Sclerosis, alcohol and drug abuse, and stroke that may result in younger onset dementia.

These organisations have agreed to work together in developing common organisational positions on the priorities agreed by consumers.

Above: Glenn Rees, CEO Alzheimer's Australia, Sharon Grierson, MP, Convenor Parliamentary Friends of Dementia, The Hon Justine Elliot, MP, Minister for Ageing, Marc Budge, President, Alzheimer's Australia. Centre: Tony Walsh, The Hon Peter Dutton, MP, Shadow Minister for Health and Ageing. Below: Mrs Margaret May MP, Shadow Minister for Ageing, The Hon Peter Dutton, MP, Shadow Minister for Health and Ageing The Hon Justine Elliot, MP, Minister for Ageing, Joan Jackman.

Action Point 1

Increased awareness to reduce stigma and social isolation

Background

'You're too young for dementia' is often the reaction of doctors, health professionals, family and friends of people with dementia because society associates dementia with 'old age'.

Awareness is the key to reducing the stigma of younger onset dementia.

Issues

- Younger onset dementia does not discriminate across culture, gender, socio-economic or any other context.
- Lack of information, awareness and understanding in the broader community, and amongst professionals and service providers, increases the stress for younger people with dementia. Friends and family struggle when others don't recognise or underestimate the difficulties that people with younger onset dementia and their family and carers experience.
- Culturally, linguistically and religiously diverse communities struggle to increase awareness and reduce stigma because the word 'dementia' is often overlaid with shame or the person being seen as "mad or crazy". Often the concept of dementia does not translate into a culturally understandable concept which further exacerbates the stigma associated with younger onset dementia.

"You're too young for dementia"

A local General Practitioner

- Younger people with alcohol-related dementia receive less empathy and often attract more judgemental attitudes in the public view.
- There is limited awareness that the person with younger onset dementia has the right to be involved in their own care.

Recommendations

1. A national awareness and social marketing program focusing specifically on younger onset dementia be developed, involving younger people with dementia telling their stories. This program should be funded by the Australian Government and developed and delivered by Alzheimer's Australia.
2. Aboriginal and Torres Strait Islander communities and culturally, linguistically and religiously diverse communities be included in awareness raising programs that are respectful of their diversity.
3. Younger people with dementia be recognised and supported in the Australian Government's social inclusion policies and initiatives including:
 - a. More inclusive workplace practices.
 - b. A greater emphasis on supporting people living with younger onset dementia in their families and in their communities.

Action Point 2

Timely and accurate assessment and diagnosis

Background

It can take many years to get an accurate diagnosis. Lack of awareness among many medical professionals means symptoms are often attributed to other life stage events such as menopause or work/relationship stress or depression. People with younger onset dementia are more likely to have rarer forms of dementia which may necessitate the involvement of many different specialists.

Issues

- Delay in diagnosis delays both treatment options and future planning.
- There is limited access to specialist diagnostic services for younger people with cognitive and behavioural changes.
- In metropolitan areas General Practitioners are the most common first point of contact. In a regional and remote area it may not be the General Practitioner but other allied health professionals. The lack of awareness and education of younger onset dementia by General Practitioners and allied health professionals can lead to delays in diagnosis.
- Rural, remote and isolated areas are more disadvantaged by the lack of specialist support available within their communities. Transport costs for travelling to medical appointments are significant and often unaffordable.

“Finding the correct diagnosis was extremely difficult and put the whole family under extreme stress for a number of years before the correct diagnosis was given” Carer

- The wide range of diseases (such as Multiple Sclerosis, alcohol related impairment, HIV/AIDS, Parkinson’s disease, Motor Neurone disease and Stroke) that can result in younger onset dementia makes the diagnosis and management particularly challenging.
- There is a general 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 variable and expensive. Most genetic tests are not listed on the Medical Benefits Scheme.
- Criteria for access under the Pharmaceutical Benefits Scheme for dementia medications are restrictive, particularly for younger people with dementia.



Above: Joan Jackman presenting the Communique at Parliament House. Below: Leo White, Ken Matthews, Tom Valenta and Governor General Her Excellency Ms Quentin Bryce AC.



Recommendations

1. A nationwide network of accessible specialist diagnostic clinics to assist people experiencing memory loss or cognitive changes be developed.
2. All health and community service professionals encompassing neurologists, nurse practitioners and allied health professionals participate in dementia awareness initiatives.
3. Dementia Training Study Centres, in consultation with the Division of General Practitioners, develop continuing education programs targeting General Practitioners, nurse practitioners and allied health professionals in dementia related issues.
4. A national framework for genetic testing be developed and implemented and supported by adequately resourced and skilled counsellors.
5. A range of appropriate and current clinical diagnostic tools be developed to streamline the assessment on younger onset dementia. Financial incentives and education strategies are needed to encourage the uptake of such tools into practice.
6. Review guidelines for accessing pharmaceuticals and diagnostic procedures for people with younger onset dementia to ensure they have access.

Action Point 3

Provide access to appropriate services

Background

Dementia can occur at any stage of life – rarely in the teens and the 20's and increasingly in the 30's and beyond. A dedicated younger onset service will have greater capacity to identify more relevant options for younger people with dementia and their families.

Issues

- Services need to be age, culturally and gender appropriate. They need to be available to all people including those living in regional, rural, remote and isolated communities.
- People who are consumers want to have a say in what happens to them.
- Support must be innovative, flexible and responsive to the needs of carers, partners and children of those with younger onset dementia. Models of care, embracing consumer directed care and empowering carers and younger people with dementia should be trialled and implemented, particularly in respect to respite care.
- Younger people with dementia living alone may need to consider 'technical aids' in their home to help maintain function, safety and independence. These may include assistive technology that promotes orientation, security, medication compliance, safe use of home appliances and communication options.

"We just don't fit anywhere"

A person with younger onset dementia

- For those families and carers who combine work and family responsibilities, respite care is critical and needs to:
 - ~ be meaningful for the person with dementia;
 - ~ be available in a form that matches the needs of the person with dementia and their family;
 - ~ be consistently facilitated by a trained support worker who should have the flexibility to provide a service to different people across different settings including regional and rural areas;
 - ~ operate outside standard business hours and include weekends.
- Long-term out-of-home care is a matter of great concern to many younger people with dementia and their families. There is a need for alternative options to be developed outside of residential aged care facilities that include the capacity to move in and out of long-term care as needs change.
- Care workers need training. Staff caring for younger people with dementia and their families require a different skill mix to meet the unique needs of younger people with dementia.
- Children of younger people with dementia are often disenfranchised of their childhood or adolescence. They may be vulnerable and at risk of many indicators of ill-being since often both parents are absorbed in the business of simply coping and adapting. Children need to be supported throughout their parent's dementia journey.

- The health of the carer is often neglected because of numerous other demands which may include young children, older parents, work commitments. Carers often lose contact with friends and family due the social isolation often experienced by people with dementia.
- Access to appropriate counselling is an essential component in assisting the person with younger onset dementia, their partner, carer, children, and parents to ensure their well-being.
 - Relationship breakdown, before or after diagnosis, contributes significantly to a lack of well-being for the whole family. Individuals, couples and families need support to maintain their relationships and respite is an important enabler in this process. The latter may be seen as an activity which can sometimes facilitate 'whole family' outings in which a support worker facilitates positive dynamics.
- Issues of intimacy and sexuality are often neglected. Health professionals need to keep open an invitation to enter the discussion.

Recommendations

1. The Australian Government, State and Territory Governments review accommodation services for people with younger onset dementia to ensure that the needs, values and expectations of younger people with dementia are identified and met.
2. A targeted strategy be implemented to improve the range and quality of in home and out of home services available for people with younger onset dementia, their carers and families including those living in rural, regional and remote areas.
3. Relationship re-engagement programs be developed as part of a suite of counselling options available for people with younger onset dementia.
4. A range of transport alternatives be readily available to allow people access to community services.
5. Programs be established to support carers to ensure that their health and well-being needs are effectively met.
6. Guidance should be provided to care staff on issues related to intimacy and sexuality to assist them in responding to the needs of people with younger onset dementia.
7. Following diagnosis, a key worker within health services be appointed (who is identified in consultation with the person diagnosed and their carer) as a single point of contact. The key worker role will be to support the achievement of short and long-term goals identified by the person with younger onset dementia and their family.

Below: Joan Oakey, Paul and Christine Bryden.



Action Point 4

Employment and Financial Needs

8. Younger people with dementia and their carers be empowered through models of consumer directed care to make decisions about the community and residential services they require.

9. A younger onset dementia funding stream be established to provide innovative approaches for age appropriate respite and long term residential care in partnership with people with younger onset dementia, their family, their carers and service providers.

10. A training strategy for health professionals and all direct care staff underpin a focus on quality care in responding to the unique needs of younger people with dementia.

11. Each Alzheimer's Australia State and Territory Office is funded for a worker to promote partnerships with culturally, linguistically and religiously diverse organisations and Aboriginal and Torres Strait Islander organisations on issues related to younger onset dementia.

12. An online directory of resources be established, funded and maintained for younger people with dementia and their families. The aim of this resource is to streamline access to appropriate up to date information.

13. Services be established to meet the social, emotional and psychological needs of children of people with younger onset dementia.

14. People with younger onset dementia remain eligible for services that are established prior to the age of 65 to ensure continuity of care.

Background

Demotion, early retirement or selling the family business (in rural communities this may be family property) are frequent outcomes of cognitive decline either before or after diagnosis. The consequence is likely to result in significant financial stress for the person and their family.

Issues

- Unemployment results in:
 - ~ Financial loss at a time of significant financial demands.
 - ~ Increase in 'alone' hours often leading to lowered self-esteem and depression.
 - ~ Increase in social isolation.
 - ~ Partners either being forced back into the workforce to meet the financial gap or being required to cease work because of their partner's increasing care needs.
 - ~ High impact on family lifestyle.
- Financial Issues:
 - ~ Person may resign prior to diagnosis without accessing their full entitlements.
 - ~ Consumers are often unaware of their entitlements in accessing superannuation.
 - ~ Cash flow problems.
 - ~ Loss of business and capacity to maintain self-employment.
 - ~ Increased medical costs.
 - ~ Some couples have to declare that they are legally separated to fund long term placement for the person with dementia.
 - ~ Carer payment and carer allowance are often denied in the first instance.

"Work called me and told me he was being sent home. It appears things had been going wrong for some time."

A spouse of a person with younger onset dementia

Recommendations

1. The Australian Government establish an advisory board of younger people with dementia, families, carers and service providers to formulate new approaches:

- ~ Remove the inequities that younger people with dementia and their family carers face accessing and maintaining their employment, in terms of superannuation and/or income security entitlements.
- ~ Review all relevant legislation to ensure that the rights of people with younger onset dementia are recognised and protected.
- ~ Review and streamline assessment processes, tools and forms to establish a person's illness, injury or disability and ensure that claims processes are simplified.

2. A program be developed and funded to support younger people with dementia in maintaining a sense of purpose and achievement through participation in full time or part time work, volunteer or recreational activities.

3. A 'Dementia Awareness in the Workplace' program be developed and made available to support employers and employees in the workplace. This program should focus on people with younger onset dementia and carers.

Above: Tony Walsh, The Hon Justine Elliot, Minister for Ageing, Joan Jackman, The Hon Peter Dutton, MP, Shadow Minister for Health and Ageing, Mrs Margaret May, MP, Shadow Minister for Ageing, Patricia Henwood, Paul Anderson. Below: Paul Wenn, Tony Walsh and The Hon Justine Elliot, MP, Minister for Ageing.



4. Employers be encouraged to retain people with younger onset dementia in employment should they wish to continue to work. As part of this initiative employment alternatives should be considered where available (e.g. the Supported Wages Scheme) and where appropriate, to ensure that employees have a range of choices before the termination of their employment is considered.

5. The Australian Government review the terminology for those who are "totally and permanently incapacitated" so as to reduce the stigma associated with disability.

Action Point 5

Legal and Bureaucratic

“Kids tormented him and we had parents take him to court and tried to have an AVO taken out against him and have him locked away because the kids were in the park... and the mother was adamant that he was going to attack them” Family member of a person with younger onset dementia

Background

Legal and bureaucratic systems, which are complex and at times inflexible, place additional burdens on people with younger onset dementia and their families.

Issues

- Access to dementia-specific legal expertise is needed after diagnosis to assist with future planning regarding powers of attorney, wills and advance care directives.
- Some people with younger onset dementia may find themselves in conflict with a legal system which has little understanding of dementia. A person with dementia may commit theft, exhibit violence and/or commit sexual misdemeanours as a result of their condition.
- Some organisations do not recognise an Enduring Power of Attorney.
- Some travel insurance policies have a ‘dementia exclusion clause’.
- Issues with private health insurance may be problematic for people with younger onset dementia.
- Younger people’s sense of identity is threatened when they are required to relinquish their driver’s licences. This situation is made more difficult by the fact that there are often few viable transport alternatives.

Recommendations

1. The Australian Government works with States and Territories to achieve greater harmonisation in legislative provisions and terminology for power of attorney and advance care directives.
2. The Australian Government ensures that the Commonwealth Disability Discrimination Act more effectively applies to people living with younger onset dementia and their carers.
3. The Australian Government establish an independent Dementia Advocate to provide legal assistance and advice to people with younger onset dementia and their carers.
4. The Australian Government works with insurance providers to ensure standard terms and conditions that recognise the rights of people with younger onset dementia in the provision of all types of insurance.
5. The Australian Government work with States and Territories to achieve more appropriate and equitable arrangements for those with younger onset dementia to support them to maintain their driver’s licence in light of their individual capacities.

Action Point 6

Research

“It is in research we will find the cure – we need to balance investment in responding to current needs while continuing to seek the cure to younger onset dementia” Health professional

Background

Quality research promotes improvement in practice which improves the quality of life of people living with younger onset dementia.

Issues

- There is inadequate information on the number of Australians who have younger onset dementia and its causes.
- There is a need for more research into disorders that affect predominantly younger people such as frontotemporal lobar degeneration and the rarer genetic forms of dementia. Most cases of Alzheimer’s disease resulting from genetic mutations occur in younger people.
- There is inadequate information about the effectiveness of different models of care.
- Dementia is not one of the priority areas of the National Health and Medical Research Council.

Recommendations

1. There needs to be greater investment into research into the cause, cure and care of younger onset dementias. This should include inherited diseases and other conditions causing dementia.
2. Research is needed to identify more accurately the numbers of those with younger onset dementia and models of care that are responsive to the needs of people with younger onset dementia and related conditions.
3. People with dementia have the opportunity to be involved in dementia research, including setting priorities and disseminating results.
4. There needs to be an initiative to encourage enrolment into brain donor programs since fundamental research into the dementias is heavily dependent upon these resources.
5. There needs to be greater awareness amongst consumers (people with younger onset dementia and their families) of centres of excellence for research particularly those participating in clinical trials.
6. Dementia should be included as a National Health Priority Area by the National Health and Medical Research Council.

Below: Richard Fogarty, Senator Marise Payne, MP, Convenor of Parliamentary Friends of Dementia, Patricia Fogarty.





**Alzheimer's
Australia**
Living with dementia

*Marc Budge, President, Alzheimer's
Australia, Governor General Her Excellency
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For advice and access to services ring the

National Dementia Helpline

1800 100 500

Alzheimer's Australia Inc ABN 79 625 582 771



The National Dementia Helpline is an
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The Governor-General, Her Excellency Ms Quentin Bryce, AC and His Excellency Mr Michael Bryce, AM, AE for their hospitality.

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Canberra

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