



Alzheimer's
Australia
Living with dementia

BACKGROUND PAPER 2009 Summit on Younger Onset Dementia

- This paper has been provided to assist those involved in pre-Summit consultations to identify the priority issues to be discussed at the Summit.
- The paper is based on the 2006 consultation report, *Exploring the Needs of Younger People with Dementia in Australia*. The report involved comprehensive consultation with people affected by younger onset dementia in all States and Territories, and is available at <http://www.alzheimers.org.au/content.cfm?topicid=55>
- Consumers should raise issues that are of most importance to them, regardless of whether or not those issues are mentioned in this paper.
- Consumers are invited to identify the priority actions they would like to see flow from the Summit.

For more information about the consultation process in your State or Territory or for information about dementia or available services contact the National Dementia Helpline on 1800 100 500

For information about the issues raised in this paper contact Alzheimer's Australia. Telephone: 02 6254 4233
Email: secretariat@alzheimers.org.au

Why is Alzheimer's Australia holding a Summit?

There is little awareness of younger onset dementia. Many people with younger onset dementia, as well as their families and carers, are currently not receiving appropriate support. While everyone affected by dementia wants timely, quality and accessible services that meet their individual needs, there are unique and complex issues faced by people with younger onset dementia and their family carers which are currently not being addressed.

Last year, Alzheimer's Australia made a number of recommendations to the Government about the needs of people with younger onset dementia, based on the outcomes of the 2006 consultation report *Exploring the Needs of Younger People with Dementia in Australia*. There was no response by the former Government before the Election was called.

The objectives of the Summit are to

1. Improve the lives of people with younger onset dementia and their families and carers.
2. Identify consumer priorities for future improvements in services and resources for people with younger onset dementia.
3. Bring to the Federal and State/Territory Governments' attention the reality that services for people with dementia are not meeting the needs of people with younger onset dementia.
4. Identify ways to improve social inclusion of people with younger onset dementia, their families and carers.
5. Promote awareness of younger onset dementia in the community.

Objectives of pre-Summit Consultation

1. Identify the most important priorities for consumers.
2. Give as many people with younger onset dementia, and their families and carers across Australia the opportunity to discuss ways to improve services and other support.
3. Reach people who are currently not using Alzheimer's Australia services.
4. Mobilise support for the Summit.

Younger onset dementia affects people and their families and carers in different ways. This paper aims to cover the key issues for most people affected by the condition.

The six major issues identified are:

1. Awareness and stigma.
2. Delays in diagnosis.
3. Access to appropriate services.
4. Employment and financial issues.
5. Impact on quality of life and legal issues.
6. Investment in research.

In reading this background paper, please consider:

- What are the key issues for people with younger onset dementia and their families and carers?
- Does this paper cover all key issues?
- What action is needed to better address the needs of people with younger onset dementia?

If we are going to succeed in influencing Ministers and their departments it would be useful for Alzheimer's Australia to have practical examples of the issues raised in this paper, such as:

- the specific barriers you may have encountered when you tried to access appropriate community or residential care services; or
- the specific difficulties you may have experienced with Centrelink.

Please raise these examples during consultation or alternatively email secretariat@alzheimers.org.au

Please note that the personal quotes used in this paper, unless otherwise specified, are from *Exploring the Needs of Younger People with Dementia in Australia*.

1. AWARENESS AND STIGMA

BACKGROUND

“rejection from the general public and their lack of understanding prevents me from making a step in trying to make friends” (54 year old man with dementia).

The approximate 10,000 Australians with younger onset dementia experience social disadvantage because of the lack of awareness of younger onset dementia in the community. The most common response made when the word dementia is mentioned is ‘old age’ yet people may be diagnosed with dementia as young as 35 years.

Lack of awareness contributes to;

- Accurate diagnosis in younger people taking longer than for older people.
- Health professionals including GPs not being aware that dementia can occur in younger people.
- A perception of stigma, social isolation, and loss of respect and social identity.
- Discrimination in the workplace.

There is no recognition of people with younger onset dementia and their families and carers within the Social Inclusion policies of the Australian Government.

SOME ISSUES

1.1 There has been no publicly-funded national awareness campaign to promote a wider community understanding of dementia.

- ❖ Such a campaign would assist in:
 - Destigmatising dementia by increasing community understanding.
 - Promoting an understanding that dementia is not a natural part of ageing.
 - Emphasising the importance of early and accurate diagnosis.
 - Getting across the idea that life does not stop with a diagnosis of dementia.
- ❖ Friends and family would be more able and willing to support a person with younger onset dementia and their family carers.
- ❖ It is not always apparent that a person has dementia. People with younger onset dementia can become frustrated when people will not accept that they have a problem simply because it is not immediately obvious. This is aggravated by a disbelief in the community that dementia can happen to younger people.

1.2 Stigma, social isolation, financial stress and poor access to services suggest that people with younger onset dementia and their families and carers should be included within the target groups of Australian Government social inclusion policies and initiatives. Lack of understanding of younger onset dementia in the community has social consequences for people with younger onset dementia and their families.

1.3 There needs to be increased understanding of dementia among health professionals in general as people with younger onset dementia can have multiple conditions and it can be difficult when health professionals involved in other fields are unaware that dementia can affect younger people.

1.4 Some people with younger onset dementia experience denial. There is a need for people to be told about their diagnosis in lay terms so that they understand from the start what is happening to them. Referral to services provided by Alzheimer's Australia and other organisations can help people come to terms with their diagnosis.

1.5 Younger people worried about memory loss or changed behaviour need to be more aware of the information that is available from Alzheimer's Australia and other organisations. Information can empower people to prompt their GP that it could be dementia.

1.6 In Indigenous communities, there is a serious lack of awareness of dementia.

2. DELAYS IN DIAGNOSIS

BACKGROUND

“No one expects it, you’re too young” (60 year old man with dementia).

“GP had no idea at all... GPs are not aware – they don’t detect it for under 65s... there were delays in diagnosis and a lot of time wasted” (Wife of man diagnosed at 55).

The diagnosis of dementia at any age is fraught with difficulties, frequently leading to a diagnosis only at a time when the person is already showing serious symptoms of dementia. This situation is exacerbated for younger people, where accurate diagnosis can take several years, causing individuals, their families and carers a great deal of anxiety.

In younger people, where dementia is less common, symptoms such as social withdrawal, memory loss, personality changes and mood swings are often initially attributed to stress, marital breakdown, depression or another mental health disorder. Such delays in diagnosis may delay treatment, affect disease progression and reduce the time available for legal, financial and care planning.

An increased awareness of the existence of dementia in younger people in the community would mean that individuals themselves would notice changes more readily and in turn, GPs and other specialists would also be more aware of the implications of such changes.

SOME ISSUES

2.1 GPs need support in developing their diagnostic skills.

- ❖ Research indicates that 94% of Australians would seek help from their general practitioners if they were concerned about their loss of memory or changed behaviour. So educating GPs is critical to increasing the rate of early diagnosis.
- ❖ Younger onset dementia is commonly diagnosed as depression. Not all GPs are aware that dementia is a possibility in a younger person.
- ❖ It is important for GPs to refer concerned people to specialists when necessary.

2.2 There is a need to develop additional specialist and multidisciplinary services to which GPs can refer younger people who are experiencing memory loss, or changes to their thinking.

- ❖ The Cognitive, Dementia and Memory Services (CDAMS) in Victoria provide a useful model. Diagnosing younger onset dementia is a complex process and extending such services would support people in obtaining a timely and accurate diagnosis.

2.3 Health professionals need support in improving diagnosis and management of younger onset dementia through awareness, education and financial incentives.

2.4 People with younger onset dementia are more likely to have a rarer form of dementia. Different causes of dementia give rise to different symptoms and behaviour changes which makes dementia in younger people more difficult to diagnose.

2.5 The progression of dementia in the younger population is generally more rapid than for older populations which makes early diagnosis critical to improving quality of life.

2.6 People who are undiagnosed may not seek medical attention because they are unaware that dementia can affect younger people.

2.7 There is a need to strengthen links between GPs and services.

- ❖ People with younger onset dementia would benefit from improved information flow across services such as collaboration between service providers and GPs.
- ❖ GPs need to be supported in referring people to useful services such as those of Alzheimer's Australia.

2.8 Special groups

- ❖ There are causes of dementia more common among younger people than older people. These include alcohol-related dementia, HIV/AIDS-related dementia and dementia among those with Down Syndrome, Huntington's Disease, or Multiple Sclerosis.
- ❖ There is also evidence indicating that Indigenous people from remote communities are five times more likely to develop dementia at a very young age (45-59 years) than the rest of the community.
- ❖ Unique targeting strategies to improve awareness of dementia and available resources need to be developed. These include stronger collaborative relationships with services for these groups.

3. ACCESS TO APPROPRIATE SERVICES

- a. Community care including day care, respite care, packages and social support**
- b. Residential Care**

BACKGROUND

“When younger people with a need for physical exercise get into groups with older, frailer people they become frustrated and show challenging behaviours. You can then get a phone call saying they can no longer attend the day care programs. If Chris can’t attend the programs, then I can’t cope with him at home. I live on the edge waiting for the phone call” (The Long and Lonely Road).

The care of people with younger onset dementia is uncoordinated and access to services varies across Australia. Very few services cater specifically for the diverse and complex needs of people with younger onset dementia.

Dementia support is usually funded through the Aged Care Program. There is a need for certainty about whether this program will continue to provide support for younger people with dementia or whether in future it will be the responsibility of disability and/or mental health programs. Lack of appropriate social support has led to the social isolation of many younger people with dementia.

SOME ISSUES

3.1 People with younger onset dementia often fall into service gaps.

- ❖ Some family carers report residential care facilities not allowing people under 65 to go on their waiting lists.
- ❖ The limited services which do accept younger people can be great distances from where the family carer resides.
- ❖ Disability programs and mental health programs do not currently cater for this group.

3.2 Problems in accessing community care packages.

- ❖ Most people with younger onset dementia would prefer to stay at home. Community care packages such as CACP, EACH and EACHD support people staying at home for as long as possible.
- ❖ Lack of access to packages in the community could mean that people with younger onset dementia may enter residential care prematurely.
- ❖ The adoption of consumer directed care might help to provide greater flexibility in tailoring packages to the needs of people with younger onset dementia.

3.3 Access to appropriate care could reduce carer burden and empower carers to have more control over their lives, such as being able to decide to continue working. Carers of people with younger onset dementia need this kind of support in continuing their everyday activities.

3.4 People with younger onset dementia and their family carers report long waiting times for permanent and appropriate residential placement.

3.5 People with younger onset dementia are generally active, mobile and physically capable. As a consequence some service providers have indicated that caring for a younger person is more demanding than caring for an older person.

- ❖ People with younger onset dementia may require a higher staff/client ratio which is expensive and potentially a deterrent to service providers accepting clients with younger onset dementia.
- ❖ Some people who do access a service may find that, because of changed behaviours, the service provider says that they can no longer care for the person. This places stress and pressure on family carers.
- ❖ The secure dementia units currently available may not be suitable for younger people.

3.6 People with younger onset dementia need socially engaging activities.

- ❖ Some younger people in residential facilities can be up to 30 years younger than the next youngest resident. Younger people with dementia have different social needs.
- ❖ People with younger onset dementia progressively lose many of the relationships on which their lives have been built. Services should promote social engagement in activities that remain important to an individual e.g. involvement in familiar activities such as going to the gym, playing lawn bowls or playing a musical instrument.

3.7 There is very limited access to flexible respite care services which embrace the principle of consumer directed care. Consumer directed care arrangements would have the advantage of enabling people to determine the type of care and who provides it.

- ❖ This may assist people with younger onset dementia in rural areas where there are not enough people with younger onset dementia for service providers to viably provide services for just this group.
- ❖ Flexible service delivery could improve services for those from culturally and linguistically diverse backgrounds and Indigenous communities.

3.8 Aged Care Assessment Teams (ACAT) need to be familiar with younger onset dementia in making their assessments.

3.9 Support workers in services such as residential care facilities and respite services need specific training in younger onset dementia. Services report a gap in appropriate training. There is a need for funding to encourage service providers to have some training in younger onset dementia.

3.10 There is a need for better information on suitable services for people with younger onset dementia and their families and carers.

- ❖ People report difficulty in finding resources which accurately describe residential care facilities and the services available.
- ❖ People from culturally and linguistically diverse backgrounds may be particularly disadvantaged.

3.11 There are other groups of younger people such as those with Parkinson's disease or Multiple Sclerosis who have similar needs to people with younger onset dementia and are experiencing similar access difficulties, for example, access to appropriate respite and residential care services.

- ❖ Alternative models of care for people with younger onset dementia might be more viable if we take a collaborative approach.
- ❖ Stronger partnerships between Alzheimer's Australia and other peak disease groups may support better services for younger people.

4. EMPLOYMENT AND FINANCIAL ISSUES

BACKGROUND

“We worry about having to take care of bills and expenses when our partner was always the main breadwinner and finances are just cut off” (Carer of person with younger onset dementia).

Employment is a significant issue for people with younger onset dementia. Many people are likely to be in employment at the onset of dementia, and this is often where initial signs of dementia are revealed.

People with younger onset dementia often leave work before they have been diagnosed, which may be distressing.

The financial situation of a younger person who gives up work may be more difficult than that of an older person who has already retired. With the progression of the younger person’s dementia, partners may need to reduce working hours, or give up work altogether to spend time caring for the person.

In some cases, people are still paying off mortgages and some have to additionally manage the cost of their children’s education and upbringing. People are worried about the prospect of financing residential care while maintaining a family home, being too young to qualify for an aged pension but having an undersized superannuation because they were forced to leave work prematurely.

SOME ISSUES

4.1 People with younger onset dementia need information and support to remain employed for as long as possible if they so desire.

- ❖ Some people with younger onset dementia would prefer to remain in the workforce in some capacity rather than be at home.

4.2 Lack of understanding of employers can lead to discrimination in the workplace.

- ❖ Many people report discrimination in the workplace and feel forced to retire because even after the diagnosis explains their change in performance, their employer can not find them work suited to their changed ability.

4.3 Disability or sickness benefits

- ❖ Sometimes people who develop dementia are forced to leave work based on apparent performance issues. However, those issues may be a result of dementia that has not yet been diagnosed. These people are then unable to take advantage of disability or sickness benefits due to delayed diagnosis.

4.4 Access to superannuation is difficult for younger people.

- ❖ By law, superannuation can only be accessed when someone reaches the minimum age set by law, known as the 'preservation age'. Individuals can have access earlier than the preservation age but many younger people report the difficulty of accessing their superannuation due to not having received a formal diagnosis. Some people report that clinicians are hesitant to diagnose dementia when they could not determine the exact type.

4.5 People with younger onset dementia have difficulty seeking financial support from Centrelink. There are inconsistencies in people's dealings with Centrelink which mean that not all people are receiving the support they should be entitled to

- ❖ Sometimes people are unable to access support even when they have evidence from doctors and specialists of their health circumstances and are not given an adequate explanation of why they aren't entitled to financial support.
- ❖ Centrelink forms can be confusing and misleading. People can be denied financial support to which they are entitled because they simply don't fill in the forms correctly.

4.6 Risk of financial mismanagement before diagnosis can cause problems for families where the person with younger onset dementia has primary responsibility for finances and their difficulty in managing their financial affairs is not noticed early enough.

4.7 Family carers often need to reduce work hours or give up work altogether to look after the person with younger onset dementia. Others may find themselves having to take up work to reduce financial burdens.

- ❖ This could be exacerbated by workplaces which are inflexible to carer responsibilities.
- ❖ Increased community understanding of younger onset dementia could alleviate some of these problems.

5. IMPACT ON QUALITY OF LIFE AND LEGAL ISSUES

BACKGROUND

"I feared the possibility of someday losing control over my own home, my own meals, my own family, and my own automobile. In short, I feared losing my last shred of dignity and control over myself" (Younger Onset Dementia Training module for careworkers and volunteers, AA SA).

When a person is young, a diagnosis of dementia is particularly traumatic because the person may be:

- In full-time employment.
- Actively raising a family.
- Financially responsible for the family.

The sense of loss for the person with younger onset dementia and their family can be enormous, in particular for young children. A carer may have to juggle employment, childcare, the care of a partner and care of an older frail parent.

Younger people are less likely to have legally planned for their future i.e. wills and power of attorney. Advance planning in the early stages of dementia is critical because once a person loses decision-making capabilities, their opportunity to have a say about their lives is lost.

SOME ISSUES

5.1 Education and counselling services with experience in dementia are needed to help people and their families deal with the huge emotional impact of younger onset dementia.

5.2 There is a lack of sufficient support for family carers. Services for people with younger onset dementia are lacking. Access to timely respite is an essential.

5.3 The impact of younger onset dementia on children has not been adequately recognised.

- ❖ Children need to be supported in understanding their parent's dementia and have access to counselling services. This includes school counsellors having a basic understanding of dementia.
- ❖ The growing numbers of people with dementia mean that more children are going to be affected by dementia whether a parent, grandparent or another relative. Children could be supported by education about dementia within the school curriculum.
- ❖ There may be concerns about whether children should be genetically tested. Counselling services need to be available before any genetic testing is undertaken.

5.4 Access to support groups, through organisations such as Alzheimer's Australia is critical. Different models of support groups may be required, e.g. telephone, social events and groups for teenage children.

5.5 Some people with younger onset dementia, as they lose insight, may have changed behaviours which are disruptive, aggressive, socially unacceptable or embarrassing to a young family. This can include loss of inhibition in public, inappropriate toileting practices or inappropriate sexual behaviour. Individuals and their family carers can become very social isolated.

- ❖ Some behaviour can be misinterpreted by people in the community and people can find themselves in complex legal situations which can have adverse consequences for the person with dementia and their families and carers.
- ❖ In court situations, people with dementia may need support which may not be currently provided.

5.6 People's sense of identity and independence is often closely tied to their ability to keep driving. The decision to give up driving is difficult for people of any age with dementia.

- ❖ It can be difficult giving up driving when the onset of dementia is so unexpected in busy lives, especially for people who have children and are no longer able to transport their kids to school or activities such as cricket on the weekend.
- ❖ There are often few other transport options, particularly in rural areas.
- ❖ Transport services may be needed for medical and other appointments.
- ❖ There is a need to have a more consistent approach to driving tests across Australia for people with dementia.

5.7 Some people with younger onset dementia may experience a loss or change in sexual intimacy with their partner. This can be a distressing experience for people of any age. Younger people may find it more difficult to accept due to their stage of life.

5.8 People with younger onset dementia may seek the opportunity to travel before their dementia becomes too far advanced. Many people with dementia and their families and carers have happy and fulfilling times traveling. This may be particularly important to people who have family overseas.

- ❖ There is reported difficulty obtaining travel insurance, with some companies having a 'dementia exclusion'.

5.9 Access to advance planning.

- ❖ People with younger onset dementia will at some point in time lose decision-making capacity. Advance planning gives people the opportunity to have a say about what happens to them, before losing capacity.
- ❖ Younger people are less likely to have appointed an enduring power of attorney or written a will.

- ❖ The current patchwork of legislation relating to advance planning is complex, varies significantly across jurisdictions and is confusing. The recognition of different laws across States and Territories is particularly problematic. Lack of education and support to make an advance plan is a major impediment.
- ❖ We need quality advance planning legislation and education, which supports the rights of people with younger onset dementia, reduces carer burden and enables individual wishes to be respected.

5.10 Since people with dementia under 65 are in the minority, they form a hidden sector of dementia-specific services or general care service client base in most areas. People with younger onset dementia face complex and unique issues and would really benefit from advocacy support services.

- ❖ Some people with younger onset dementia and their families and carers won't always have the knowledge and skills to exercise their rights and may need support in being able to participate as full members of the community.

6. INVESTMENT IN RESEARCH

BACKGROUND

Increased investment in dementia research will have a positive impact on all people of any age affected by dementia, but particularly younger people who are far from their natural end of life span and suddenly need to dramatically revise their expectations of everyday life.

Investment in dementia research, whether in cause, cure or care, is a key strategy for addressing the increasing numbers of people with dementia. Historically, medical research in Australia has produced returns of \$5 for every \$1 spent.

Younger people are more likely to experience a wider variety of types of dementia and therefore there needs to be increased research into the different types of dementia including vascular dementia, frontotemporal lobar degeneration, HIV-related dementia and less common causes of younger onset dementia.

IDENTIFIED ISSUES

6.1 There is a need to increase awareness of younger onset dementia amongst researchers and academics.

6.2 Research is needed to identify more accurately the numbers of those with younger onset dementia, where they live and their underlying conditions.

6.3 There needs to be greater research into improved diagnostic tools for dementia so that we are able to diagnose dementia much earlier.

❖ Delays in diagnosis may delay treatment, affect disease progression and reduce time available for legal, financial and care planning.;

6.4 There needs to be more research into quality dementia care for younger people and resources to ensure research translates into practice.

6.5 There is inadequate investment into dementia research overall

Relative to current disease burden and current direct cost of care, dementia research in Australia is significantly under-funded. Annual expenditure on dementia research is currently \$12.8 million (0.57% of the total direct cost of dementia). In comparison with other major diseases, this is about:

❖ 50% of research funding for cancer, relative to current disease burden. 30% of research funding for cardiovascular disease, relative to current direct cost of care. 20% of research funding for cancer and diabetes, relative to current direct cost of care. 5% of current research funding for cancer relative to predicted direct cost of care in 2023.

RESOURCES

Alzheimer's Australia

- *Understanding Younger Onset Dementia*, Quality Dementia Care Series, Number 4, 2008, Available at <http://www.alzheimers.org.au/content.cfm?infopageid=4698>
- *Exploring the needs of younger people with dementia in Australia*, Report, 2007, Available at <http://www.alzheimers.org.au/content.cfm?infopageid=2746>
- *The Long and Lonely Road; Insights into living with younger onset dementia* available at <http://www.alzheimers.org.au/upload/LongLonelyRoad.pdf>
- *2 Young 4 Dementia*, 2008. (A resource developed by Alzheimer's Australia ACT to educate service providers about younger onset dementia).
- *Younger Onset Dementia Training Module for Careworkers and Volunteers*, 2008. (A resource developed by Alzheimer's Australia SA).

Other resources

- *Services for younger people with Alzheimer's disease and other dementias*. Royal College of Psychiatrists and Alzheimer's Society London, Council Report CR 135, 2006.
- *Appropriate HACCC Service Models of people with younger onset dementia and behaviours of concern*. NSW Department of Ageing, Disability and Home Care, 2007.
- *HACC Service Models of people with younger onset dementia and behaviours of concern: Issues for Aboriginal and Torres Strait Islander People and People from Culturally and Linguistically Diverse Backgrounds*. Community Care (Northern Beaches), 2008.