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(Dementia)
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House of Representatives Committees. House Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

Submission from Alzheimer's Australia Vic

May 2012

Context

This submission relates to the experience of dementia diagnosis and intervention in Victoria. National evidence and recommendations are documented in Alzheimer's Australia submission and international evidence is well documented by Alzheimer's Disease International.[1]

In this submission 'early diagnosis' will be replaced by the preferred term of 'timely diagnosis'. Alzheimer's Australia recommends this terminology because new diagnostic criteria and biomarker screening technologies can allow examination of the presence of brain pathology at presymptomatic stages with associated social and ethical ramifications. A timely diagnosis co-incides with action at the point of first expressing concern and the provision of diagnosis as well as advice, treatment and support services.

Addressing the terms of reference provides challenges due to the lack of funding for social research dollars associated with dementia. In the absence of published Australian research, consumer consultation and anecdotal evidence, for the most part, provides the basis for this submission.

Alzheimer's Australia Vic is in an excellent position to reflect on the specific needs of people with dementia and their family carers in the early stages of the disease. Alzheimer's Australia Vic consults regularly with its consumers through its Consumer Advisory Committee, Younger Onset Dementia Reference Group and Dementia Action Register.

People with dementia and their family carers have important understanding and experience of living with dementia. This submission reflects their experience of diagnosis and intervention as their journey provides a unique insight for informing dementia policy, plans and service.

Dementia explained

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. Most people with dementia are older, but not all older people get dementia and it is not a normal part of ageing.

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[1] Alzheimer's Disease International. World Alzheimer Report 2011. The benefits of early diagnosis and intervention.

Dementia in Victoria

It is estimated that there are currently almost 72,000 people in Victoria with dementia[2]. This is projected to increase to almost 246,000 people by 2050, representing a 244% growth in prevalence between 2012 and 2050.[3] This growth is primarily driven by population ageing, although modifiable lifestyle risk factors (similar to other chronic diseases) will also play a role.

Alzheimer's Australia Vic was established in 1983 by a group of carers concerned about the lack of information, resources and support available for people living with dementia. Today it is Victoria's peak organization providing leadership in dementia policy, risk reduction and services.

Managing the dementia epidemic presents huge and growing challenges in terms of costs and burden of disease. However, with timely diagnosis, appropriate intervention, age-friendly and dementia friendly environments, good community care and investment in research, it is possible to minimise these burdens and live positively with dementia.

Diagnosis in Victoria

Dementia may be diagnosed by a General Practitioner (GP), specialists (such as neurologists, geriatrician, psychogeriatricians, psychiatrists, neuropsychologists), Aged Care Assessment Teams (ACAT) or memory clinics.

Memory Clinics are the Victorian government Cognitive, Dementia and Memory Service commonly known as CDAMS. It is a specialist multidisciplinary diagnostic, referral and educational service for people experiencing memory loss or changes in thinking.[4] It is unique in Australia as the only Government funded specialist service for people with memory concerns.

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. Delays in diagnosis occur for a number of reasons, including the belief that memory problems are a normal part of ageing, perceived stigma attached to dementia, the lack of a cure as well as fear of the future.[5]

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[2] Deloitte Access Economics. Dementia Prevalence in Victoria. A Summary. April 2012. Commissioned by Alzheimer's Australia Vic

[3] ibid

[4] Cognitive Dementia and Memory Service. What is CDAMS? www.health.vic.gov.au/subacute/cdams.htm

[5] Early diagnosis of Dementia. Alzheimer's Australia. Paper 10. March 2007. p.1

Improve quality of life and independence

Discussions with people living with dementia indicate a number of important opinions on how early diagnosis and interventions can improve the quality of life and assist people with dementia to remain as independent as possible:

Common diagnostic pathways

The diagnostic path often starts with a GP. I believe the GP's need to be better informed about dementia particularly where a younger person is involved. Stress seems to be often used as a "cop out". I feel it is vital that a common diagnostic pathway is followed where there is any inkling of cognitive impairment. (Judy, cared for her husband who had dementia)

The Victorian memory clinic model can assist in providing a common diagnostic pathway. CDAMS provides a comprehensive multidisciplinary assessment by knowledgeable staff, availability of statewide co-ordinated network of clinics, at no cost to the consumer and the option of either referral from doctors and health professionals or self-referral.[6]

A review of CDAMS in 2003 by the Australian Institute for Primary Care[7] found significant benefits for clients:

- Open acceptance and understanding of clients concerns about memory was an empowering change[8]
- Diagnosis, information and advice on the condition
- A positive impact on people's lives[9] - 39% improved client wellbeing, 39% improved carer morale (note small survey sample n= 53)

The evaluation interestingly found that 32% of clients lived alone[10], indicating the importance of service providers to refer and follow up proactively with clients to ensure they are networked into support services.

The country of birth profile of CDAMS clients also reflected those of Victoria's older population which is interesting given there has been evidence that people from some culturally and linguistically diverse (CALD) backgrounds tend to present later for diagnosis.[11]

Appropriate and prompt referral after diagnosis

Whilst, according to the 2003 review, CDAMS was performing well at diagnosing dementia, there were areas identified for improvement. These included waiting times, availability of services in particular rural Victorian locations, lack of follow up and lack of

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[6] Review of the Cognitive, Dementia and Memory Clinics. A Report Prepared For The Department of Human Services. Final Report. Australian Institute for Primary care. Lincoln Gerontology Centre. January 2003.

[7] ibid

[8] Ibid p

[9] Ibid p. 70

[10] Ibid p 27

[11] Access Economics. Dementia prevalence and incidence amongst Australians who do not speak English at home. November 2006. http://www.alzheimers.org.au/research-publications/access-economics-reports.aspx

ongoing support for carers.[12] For example, in 2002, rates of CDAMS clients referred back to GPs were high, but only about 48% of clients were referred to Alzheimer's Australia Vic[13]. Reassuringly these figures would now be significantly higher as CDAMS and Alzheimer's Australia Vic have established strong relationships which provide for ongoing community support post diagnosis.

Consumer feedback confirms concern about referral after diagnosis. The following two examples demonstrate how deficiencies may occur in the referral pathways.

The initial GP consultation was handled very well and we were quickly referred to CDAMS…. The specialists at CDAMS and the community nurse were extremely helpful and caring…. The subsequent referral was to a totally inappropriate Specialist Neurologist lacking preparation, background and understanding of our case…The problem would seem to be that CDAMS is a diagnostic service only and does not receive enough feedback from the referrals they make. Otherwise they clearly would not make referrals to specialists that have such a poor outcome
Terry, cares for his wife with younger onset dementia (Posterior Cortical Atrophy)

The initial reaction after diagnosis was denial by my spouse and confusion for me. I had poor support and knowledge, poor understanding of the next phase and some reluctance to look too far ahead (Gavin, cares for his wife with dementia)

If we had help at the beginning all the points [in the submission terms of reference] would have been better and more. It is a no brainer that if help is available to someone who needs it they are better able to cope. (Robyn, cares for her mother who has Alzheimer's Disease)

Appropriate levels of timely information

Consideration of how much information people can process when they are still in 'shock' from the diagnosis must be taken into account. Follow up services can support people in making decision at a pace where people are able to manage.

Once diagnosed she was dismissed. I was given an A4 envelope of about 100 brochures and we were shown the door. It did turn out that some of those brochures were important – like the one introducing us to AAV, but it looked like a pile of junk mail so I 'filed' it. It also took me about 2 more years to find out there were services that specialized in dementia care and also about HACC, CACPs etc. (Robyn, cares for her mother with Alzheimer's Disease)

If the diagnosis had been a more personal and caring experience I don't think it would have been such a gut-wrenching struggle at the start. I had no-one to help me (I am an only child and my mother is a widow) and I didn't know where to turn. At one point my life was really spiraling out of control. (Robyn, cares for her mother who has Alzheimer's Disease)

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[12] Review of the Cognitive, Dementia and Memory Clinics. A Report Prepared For The Department of Human Services. Final Report. Australian Institute for Primary care. Lincoln Gerontology Centre. January 2003. p 69

[13] Ibid p. 41

Ongoing guidance and support to make decisions

In 2011 the Department of Health and Ageing (DoHA) commissioned Alzheimer's Australia to conduct a series of consumer consultations in response to the Productivity Commission's report *Caring for Older Australians*. Sixteen consultations and contact with over 1000 people indicated that the quality of life of people with dementia is very much impacted by issues in the health system. Consumers are not just looking for information but also want guidance and support to make decisions. Consumers indicated a desire for a single 'case manager' or 'dementia nurse' who could support them throughout the journey from diagnosis, assessment to decisions about residential and community care[14]

Opportunities to take a break

Most people with dementia wish to live at home as long as possible. Regular, flexible respite and home services are essential requirements to allow a person in the caring role to remain socially connected and able to cope. Assistance must be relevant, family centred and proactively arranged.

The biggest problem I see is that services are not accessed early enough and there appears to be a massive gap between the initial support provided by Alzheimer's Australia and when other services are accessed. Unfortunately it often takes a crisis in the home for services to be sourced…. The important thing is for the support to be as relevant as possible which means careful matching of support staff to clientele to keep people with dementia participating in activities they enjoy. (Judy, cared for her husband who had dementia)

Hundreds of carers and organisations have previously submitted evidence to the House of Representatives Standing Committee on Family, Community, Housing and Youth in 2009 of the essential need for adequate amounts of 'time out' from the caring role, and increased access to counselling, if their psychological and emotional well being is to be maintained[15].

My concern is that my mother who is in her 80's too, and the main carer for Dad, will become too tired to manage. She had a lunch the other day and the table setting Dad did was spatially incorrect. She has been advised of a wood working group that may be good for Dad but he becomes agitated with any additional plans plus he doesn't really like doing anything new. The community aspect would only be of assistance really to mum who requires the break and stimulation of others. (Anna, cares for her father who has dementia)

Independence is a particularly emotive issue for people living with younger onset dementia (YOD). They desire services that are not aged care services, particularly in the provision of respite and residential care as described by the following two case studies.

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[14] Report for the Department of Health and Ageing in relation to services for Effective Consumer Engagement in the Aged Care Reform Process. Alzheimer's Australia. December 2011. p. 26

[15] The Parliament of the Commonwealth of Australia. *Who Cares…? Report on the inquiry into better support for carers.* House of Representatives. Standing Committee on Family, Housing, Community and Youth. April 2009. Canberra

*For YOD one of the greatest needs is for them to be considered a disability in its own right and not just an older person's disease that has come early. (*Terry, cares for his wife with younger onset dementia [Posterior Cortical Atrophy])

In my experience though when the caring process became really difficult the services were nowhere near sufficient for me to confidently keep Paul at home. Paul was extremely active and "into everything". Respite in the low care facility and attendance at PAG and Men's Group were abruptly ceased. No notice and no consultation! I was left feeling I had no other option but to place Paul in an Aged Care Facility which was totally inappropriate for his age and physicality. (Judy, cared for her husband who had dementia)

Alzheimer's Australia Vic responded to the need for social support for the YOD cohort in 2009 by offering a support and advocacy group for people who receive a diagnosis before the age of 65.

Health and lifestyle management

Early interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalisation[16].

Some interventions may be more effective when started earlier in the disease course. For example, medications such as cholinesterase inhibitors provide limited benefits for people in the later stages of Alzheimer's disease.[17]

Changes in memory and thinking ability can be very worrying. Timely diagnosis allows prompt access to medications as well as health and lifestyle management.

Models for independence have also been implemented. The Victorian government Home and Community Care (HACC) Active Service Model focuses on promoting capacity building and restorative care in community care service delivery. The goal of the Active Service Model is to assist people to live in the community as independently and autonomously as possible. In this context, independence refers to the capacity of people to manage the day to day activities of their daily life and autonomy refers to making decisions about one's life[18].

Whilst dementia is a degenerative and incurable disease, international research into cognitive rehabilitation, restorative therapies and the non-pharmacological treatment of dementia has been undertaken over many decades. Restorative Therapies give hope, purpose, enjoyment, independence and bring quality of life back into the equation.[19] In Australia, the Dementia Collaborative Research Centre (DCRC - assessment and better care) at the University of NSW promotes research translation including non-pharmacological interventions for dementia.[20]

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[16] World Alzheimer's R eport 2011. The benefits of early diagnosis and intervention. Alzheimer's Disease International. P. 5

[17] Alzheimer's Australia. Update Sheet 1. Drug treatments for Alzheimer's Disease – Cholinesterase Inhibitors. June, 2011

18 Active Service Model Project http://www.health.vic.gov.au/hacc/projects/asm_project.htm

[19] http://www.churchilltrust.com.au/site_media/fellows/2009_Kelly_Anne.pdf Accessed May 1 2012

[20] www.dementiaresearch.org.au

Alzheimer's Australia also promotes a restorative approach to dementia care. A new professional education course provided by Alzheimer's Australia Vic provides the knowledge to develop and deliver Montessori based activities as part of a cognitive rehabilitative therapy model.[21] These courses require significant funding injection for expansion.

Opportunities for continued social engagement and community participation

Public awareness and support

The stigma associated with dementia can often lead to social exclusion, discrimination, and disempowerment. Dementia is the second most feared disease after cancer and almost 77% of carers of people with dementia have at some time felt embarrassment or shame.[22]

Coping as carer with the many implications of this progressive illness…the social stigma… resignation from services such as Probus. (Gavin, cares for his wife who has dementia).

The time comes when you can no longer attend social functions; no longer go out to restaurants or even the movies…isolation creeps up on you…spending most of your days with a dementia sufferer can destroy your morale and make you doubt your own sanity…you can only look after someone else's health if you are healthy. Respite is only part of the deal...(Tom, cared for his wife with YOD)

People with dementia call for recognition of their retained abilities to increase their capacity for social inclusion.

In 2011 Alzheimer's Australia Vic highlighted participation enablers in the submission to the Parliament of Victoria *Inquiry into Opportunities for Participation of Victorian Seniors*. These included dementia friendly environmental design, technology, adequate and timely support for carers, investment in social research, brain health promotion programs (dementia risk reduction), timely diagnosis and improved access to quality dementia care.

Dementia Intervention & Support Services

Alzheimer's Australia Vic provides support to the person with dementia and their family carers. Services include:

- National Dementia Helpline telephone service that responds to requests for information and for talking about concerns
- Professional one on one or family counselling

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[21] http://www.fightdementia.org.au/common/files/VIC/Program_flyers_Accredited_Rehabilitative_Therapies-_unit_1.pdf Accessed May 1, 2012

[22] Alzheimer's Australia NSW. Addressing the Stigma associated with Dementia. Discussion Paper 2, September 2010

- Living with Memory Loss – a time limited educational and social support group for people with early stage dementia, their family and friends
- Memory Lane Café which is an ongoing longer term social support group for the person with dementia and family carers.
- Family carer educational workshops

In 2012 there are 14 café events throughout Victoria, with demand creating a need for further expansion.

In 2008 the National Ageing Research Institute evaluated Alzheimer's Australia Vic Memory Lane Cafés. At the time there were three Memory Lane Cafés in Victoria. The aim of the evaluation was to provide information about the performance of Memory Lane Cafés, including the service model, profile of clients, impacts and potential improvements. Whilst Memory Lane Café's extend beyond early intervention, they are similar in nature to the early intervention Living with Memory Loss Program, and thus one may expect some translation of evidence.

Major findings from surveys and focus groups with clients indicated that the service model benefits social and emotional well-being of clients by providing:
• A venue for people with dementia and their family members and carers to socialise where the behavioural symptoms of dementia were accepted.
• Mutual support for people with dementia and their family carers through linking with others with similar circumstances associated with living with dementia.
• Information and education regarding links to support services, including Alzheimer's Australia Vic programs, and respite care.
• An enjoyable social occasion that clients looked forward to.

Key success factors of café style support included[23]:

- Opportunity for both people with dementia and their family or friends to attend together
- Being in an environment where behaviours associated with dementia are accepted
- Opportunity for a range of access points from other programs or services
- Social nature of the program
- Peer support
- Continuity – opportunity for ongoing support, particularly for the carer – even after the person with dementia may have moved into residential aged care or died.

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[23] Evaluation of Alzheimer's Australia Vic Memory Lane Café's. National Ageing Research Institute for the Victorian Government Department of Human Services. November 2008. p. 69

'…we've got a lady with frontal lobe dementia and she bangs on the table and she sings and everybody's fine with that. She gets really excited about things and she can do that. She can knock over a glass and nobody's going to be shocked…'[24]

Whilst the 'café' program is a social peer support model it also provides education opportunities through the attendance of professional counsellors who can inform and provide guidance.

Carer stress may be very high when living with a person with dementia for a variety of reasons. It is often in response to the behavioural and psychological symptoms of dementia (BPSD) and the changes in the relationship that occurs with the personality changes that dementia may bring. A new eight week course responding to consumer demand for managing stress has been developed specifically for people in the caring role. Called *Coping with Carer Stress*, counsellors utilize cognitive behavioural therapy techniques to assist people with coping, particularly in relation to BPSD. Initial feedback appears very promising and other non-dementia related agencies have also contracted staff to offer this service.

Non-pharmacological interventions provide the potential to support cognitive function, delay institutionalization, reduce carer strain and psychological illness and improve quality of life[25] Alzheimer's Australia Vic therefore supports and recommends these approaches in relation to managing the behavioural and psychological symptoms of dementia.

Planning for the future, including organising financial and legal affairs and longer term care requirements

Some of the strongest arguments for timely diagnosis and intervention relate to the choice this allows. Choice to make informed decisions about the future and time to allow people to find the best available options to suit their situation;

A benefit is that we have had the opportunity to speak with various specialists in the field and find the best and most suitable medical management for him at this time. (Anna, cares for her father who has dementia)

Timely diagnosis allows the person with dementia to arrange their own financial and legal affairs rather than this falling to family members in a crisis.

The following examples demonstrate how timely diagnosis allows a proactive approach to financial issues. Unfortunately the diagnosis does not ameliorate the issues of service system navigation or carer entitlement difficulties.

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[24] Ibid. p. 39

[25] World Alzheimer's R eport 2011. The benefits of early diagnosis and intervention. Alzheimer's Disease International. P. 8

Mum and Dad have coped very well here because they were prepared. A number of the doctors have made suggestions here also so I don't think this [advance care planning] is something the doctors are unwilling to address. It is more social 'solutions' that we are not being communicated – social worker kind of issues, things such as driving options, cleaning assistance and food assistance. (Anna, cares for her father who has dementia)

Luckily Mum's Alzheimer's has been extremely slow to progress so we have had time to get some forward planning in place. For example a year or so after diagnosis I heard about Power of Attorney forms so we were able to get those in place before it was too late. Financial arrangements are really in a 'holding pattern' because it is not possible to forward plan when you don't know the time mum will be in care full time. This is far from ideal as we are all playing a nervous waiting game. The financial problems aren't really the fault of the diagnosis though; it is more the inability of the pension system to keep pace with the unpredictability of the disease.
(Robyn, cares for her mother who has dementia)

The following case study demonstrates that delays in diagnosis can have significant financial implications for the entire family. Advice about advance care planning can also come from a variety of sources.

This [delay in diagnosis] was extremely frustrating. We felt we were in limbo the whole time and it seemed as though we were travelling to appointments "here, there and everywhere". Paul couldn't understand why the medications weren't working and why he couldn't go back to work. We ended up getting great financial advice from the Vic Teacher's Union with regard to using all of the accrued Sick Leave and Long-Service Leave. At the time our eldest was at Melbourne University, not eligible for Youth Allowances, so her living away from home costs were significant. Within two years our second daughter was at Uni in Melbourne also, so we had two students in College accommodation….Our contact with Professor X [name removed] set the ball rolling. He immediately informed us about Occupational Therapist driving tests and getting POA's and Guardianship in place and revisiting Wills. He also passed our names onto AA and the regional consultant made contact with us.

How best to deliver awareness and communication on dementia and dementia related services in the community

There is little doubt that there is confusion about the availability of dementia related services, navigating the service system, as well as the much broader need for knowledge and understanding of dementia.

I am not sure what support is available for mum in the home still. Who is the body we should be receiving this information from? … My sister, myself and brother all live regionally so we do need to understand what services are available [in the city] and when mum and dad would qualify for these. (Anna, cares for her father who has dementia)

The Report for the Department of Health and Ageing in relation to services for Effective Consumer Engagement in the Aged Care Reform Process indicated a key concern was delays in diagnosis and failure to refer to support services. The report indicated that the dementia journey needs to start with a timely diagnosis, referral to support services, properly resourced assessment services and a link worker (not a call centre) to provide guidance when needed[26]. Consumers can be flooded with information and do not know how to choose services. A 'key worker' who understands the needs of people living with dementia, as well as the services available, would be very valuable.

Consumers are not looking just for information but also want personal guidance and support.

Our older rural generations still appreciate the personal approach. They want personal visits from representatives. They are not very computer savvy. (Judy, cared for her husband who had dementia)

The concept of a proactive ' key dementia worker' (also referred to as 'dementia nurse', 'link worker' or 'case manager') who guides a person to navigate and choose services in a continuous manner throughout the dementia journey is a regular theme Alzheimer's Australia Vic hears in dementia related consultations. Various models of care have been suggested by consumers, mostly encouraging direct face to face contact. Suggested models for examination are those of other chronic diseases such as diabetes educators connected with community health or hospitals, or breast cancer care nurses. Other models consumers recommend are those used by Victoria's maternal child health sector.

For awareness and communication on dementia and dementia-related services into the community I would like to have nurses or co-ordinators that manage people diagnosed in their 'boundary'/region immediately – much the same way as a 'maternal child and health' specialist. (Anna, cares for her father who has dementia)

Access to a person who will follow through with assistance and provide ongoing information in a timely manner can assist people coming to terms with a diagnosis.

Make it [diagnosis] a more caring and personal experience. Possibly a large public hospital is not the place for this….at diagnosis Mum was in complete denial and I had really no concept of what Alzheimer's really is. Before they let you leave their care the hospital should ensure you understand what they have told you. Mum and I certainly didn't! (Robyn, cares for her mother who has Alzheimer's Disease)

Awareness and communication is not only about public education but also requires the health, medical and other service providers to communicate and work well together. Consumer consultation indicates a desire for diagnostic services to be integrated with the whole health system. In particular there was a desire to see diagnostic services/doctors/specialists arrange a *direct referral* to services such as Alzheimer's Australia.

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[26] Report for the Department of Health and Ageing in relation to services for Effective Consumer Engagement in the Aged Care Reform Process. Alzheimer's Australia. December 2011.

It would have been better if we had practical non academic support of the condition. Alzheimer's Australia does not seem to get a record of his diagnosis to then be proactive and send literature regarding support programs etc. I may be incorrect here – as sometimes Mum and Dad do miss these first introductions. Perhaps if this kind of information was in writing from the specialist neurologist rather than the scientific and academic diagnosis which was first handed to us with his initial diagnosis. (Anna, cares for her father who has dementia)

A range of views were expressed on awareness and communication about dementia and dementia related services. There were suggestion for large mass media style television awareness campaigns. An important step seen was to continue to work on minimising misperceptions and the adverse stigma of dementia.

The perception of dementia needs to change. It is seen as an aged related illness and commonly as a mental illness (or at least someone who has lost their mental faculties). Whereas the loss of parts of the brain function may be likened to other body parts wearing out. The big difference is that the brain cannot be replaced (unlike a knee or a hip or even an organ like the heart). One way to deliver awareness and communication on dementia is to uncouple it from an age related disease and call it "brain disease" in the same way as heart problems are referred to as heart disease. (Terry, cares for his wife with younger onset dementia [Posterior Cortical Atrophy])

Radio and television are powerful mediums. I feel it is very important to present a positive view of dementia, to be aiming for acceptance within the community (Judy, cared for her husband who had dementia)

Recommendations

A range of initiatives are required to assist people to remain independent and engaged in the community:

1.0 Reduce the misunderstanding of dementia, including stigma and the associated social exclusion through public education and awareness programs characterized by positive and simple messages[27]. Dementia is not a normal part of ageing and entails more than a simplistic view of memory loss.

  1.2 Promote positive dementia role models and dementia champions.

2.0 Develop, implement and evaluate social inclusion programs focused on leisure and access.

3.0 Ensure availability of appropriately resourced support services which allows the carer and person with dementia to maintain family, social and community relationships.
  3.1 Provide flexible dementia friendly home and community care services, including expanded availability of consumer directed care

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[27] Alzheimer's Australia NSW. Addressing the Stigma associated with Dementia. Discussion Paper 2, September 2010

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4.0 Expand available dementia education and professional development for doctors, health professionals, dentists and other care workers and ensure that it focuses on a holistic approach to dementia care.
    4.1 Education and implementation of independence and rehabilitative models as part of good dementia care.

5.0 Investment in greater social research into the effects of living with dementia on both people with dementia and their family carers.

6.0 Ensure availability and access to adequately prepared, networked, trained and resourced diagnostic and intervention services that deliver.
    6.1 Enhanced co-ordination of diagnostic and community services with improved communication about services to clients
    6.2 Seamless and efficient transition from diagnostic to support and care services

7.0 Fund proactive and sustained follow up by community support services, including Alzheimer's Australia
    7.1 Review models from other chronic health conditions in order to examine the feasibility of implementing the 'key dementia worker' concept.

Timely diagnosis is a cost effective investment for government with early diagnosis and intervention offset by savings from delayed institutionalization.[28] This inquiry provides an important opportunity to reflect on the needs of people living with dementia to access timely diagnosis and intervention. Increasing rates of dementia will increase demand for diagnosis and this needs to be met with adequately prepared and resourced services as well as a range of other interventions highlighted in this submission.

Acknowledgements
With thanks to Alzheimer's Australia Vic Consumer Advisory Committee and Younger Onset Dementia Reference Group – the people who are on the dementia journey and whose words are featured in this submission.

Dianne Biermann
Policy Officer
May 2012

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[28] World Alzheimer's R eport 2011. The benefits of early diagnosis and intervention. Alzheimer's Disease International.

ERA

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ELDER RIGHTS ADVOCACY

27th April 2012

Dr Alison Clegg
Committee Secretary
House of Representatives Standing Committee on
Health and Ageing
P.O. Box 6021
Parliament House
Canberra ACT 2600

Dear Dr Clegg

I am writing in support of the submission by Alzheimer's Australia Vic, on the Senate Standing Committee's *Inquiry into dementia: early diagnosis and intervention.* Elder Rights Advocacy(ERA),is an independent agency funded by the Commonwealth Department of Health and Ageing (DOHA) to provide advocacy services for people receiving Commonwealth funded aged care services in Victoria. It is part of the National Aged Care Advocacy Program (NACAP), and has been advocating for care recipients since 1990.

We also assist carers and family members who represent the interests of people receiving aged care services, as well as people who have been assessed as eligible for a Commonwealth funded aged care service.

ERA'S ROLE

We provide a unique service to individuals through our model of advocacy that focuses on helping older people (or their representatives) to understand and exercise their rights, and to have those rights respected in the delivery of their care services.ERA works to protect the rights and well-being of frail and vulnerable older people and work towards their social inclusion. We assist them to exercise their legal capacity, to make and contribute to decisions about their lives and to participate in processes directed towards improving the quality of the care and support they receive.

In our role as advocates we become aware of the concerns raised by many people and their family members around accessing a timely diagnosis of dementia, and the support and information needed by them and their families at this time. We frequently hear that even after diagnosis people felt alone, swamped by information and fearful of their future. In this situation we believe it is vital that appropriate support services, and a clear pathway to access support are available to them.

The ability to maintain social connections, so vital to the wellbeing of the person and their carer, is also dependent on access to well -resourced services, including home and community care. We would therefore wholeheartedly support the recommendations in the Alzheimer’s Australia Vic submission.

We look forward to the Committee’s final report, and to a greater focus on positive interventions to improve the quality of life for people living with dementia into the future.

Yours sincerely

Mary Lyttle
Chief Executive Officer
Elder Rights Advocacy