

NSW HACC ISSUES FORUM

Address for Correspondence: NCOSS, 66 Albion St, Surry Hills NSW 2010 Ph (02) 9211 2599

11 May 2012

Mr Steve Georganas, MP
Chair
Standing Committee on Health and Ageing
c/o Committee Secretary,
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600
By email: haa.reps@aph.gov.au

Submission No. 085

mal (Dementia)

Date: 11/05/2012

Re: Inquiry into Dementia: Early diagnosis and intervention

Dear Mr Georganas

The NSW HACC Issues Forum appreciates the opportunity to provide feedback to the House of Representatives Standing Committee Inquiry into dementia: early diagnosis and intervention.

The NSW HACC Issues Forum brings together a range of stakeholder representatives in the Home and Community Care (HACC) Program in NSW, including regional HACC Development Officers, other statewide policy and development networks, statewide local government organisations, non-government provider organisations, and statewide consumer peaks. The NSW HACC Issues Forum meets six times per year to consider program-wide policy, planning, access issues, and developments. The Council of Social Service of NSW (NCOSS) provides secretariat support to the NSW HACC Issues Forum.

The NSW HACC Issues Forum compiled the following comments in response to the Terms of Reference of the Inquiry after a workshop conducted at its meeting held on 12th April 2012, attended by 25 members. Further feedback was provided by telephone and email from other members.

The HACC Program provides a range of services to eligible people with dementia. In addition to general HACC services, there are a range of specific services within the HACC Program for people with dementia, including dementia day services, respite services, social support monitoring, case management, and information and advisory services. People with dementia make up a large constituency of the target population for the HACC Program. This submission is concerned with people with dementia living in the community, rather than those living in residential aged care.

The HACC Issues Forum supports a person-centred approach to support and care for people with dementia. This includes centring the decisions of the person, and building support around their interests, passions and choices.

Benefits of Early Diagnosis and Intervention

HACC services provide considerable essential early intervention support to people with dementia. As eligibility for HACC services is based on relative functional capacity, HACC service providers often support people with dementia prior to their obtaining a formal diagnosis. As such, HACC providers are very familiar with how

early intervention and diagnosis can improve a person's quality of life, assist people to remain independent, increase community and social connectedness, and support planning for the future.

People with dementia who have access to early diagnosis and intervention often experience a better overall quality of life than those who do not. Obtaining diagnosis is often a major barrier to accessing further clinical and social support.

Community care intervention at an early stage often allows people with dementia to avoid crises and to plan more effectively. In some cases it may also delay a person's entry into residential aged care. Early diagnosis and medical management can positively affect disease management in early stages and reduce family stress, and also the financial burden of seeking multiple tests and consultations with specialists.

Providing information, education and support through Living with Memory Loss programs, carer support groups, blogs, individual and family counselling supports families in many ways. Some of the benefits of community-based social support through existing initiatives offered through HACC and other services include making informed decisions, addressing grief and loss, making healthy adjustments to lifestyles, addressing safety issues and concerns, and providing the words and language to positively share their stories with others to build a support network for the person with dementia to reduce misinformation and social isolation. Restorative care and rehabilitation programs that address specific motor, visual and or language difficulties, provide advice on aids and equipment, advise on home modifications or provide a program of exercise can assist to remediate difficulties and maintain function longer.

Accessing early diagnosis and intervention is often critical for a person to make preparations for times where they may require supported or substitute decision-making about their health, care, financial and legal affairs. Undertaking advance care planning, putting in place enduring guardianship orders and enduring powers of attorney, all require time and clarity. It is often difficult for people with dementia and their carers and families to make these arrangements during crisis periods where a person has limited capacity to participate in decisions.

Often, the benefits of early diagnosis and intervention are highly specific to the person and relate to the quality of aspects of their lives that matter especially to them.

Recommendation 1.

That the Australian Government invest in more basic level community care support for people with dementia.

Barriers to Early Diagnosis and Intervention

There are significant barriers to accessing early diagnosis and intervention for people with dementia. Many of these involve the considerable stigma associated with dementia, which manifest in families, communities, and in the health system.

Stigma related to dementia is related to ageism and stigma about mental illness. Age discrimination often manifests as a dismissal of older peoples' contributions as irrelevant due to declining cognitive capacity, as does discrimination towards people with mental health conditions. In some cultures and/or languages, words for dementia have a strong negative connotation and association with mental illness.

Addressing stigma is a prerequisite for addressing barriers to early intervention and diagnosis.

These barriers include:

- The uneven distribution of neurological and gerontological specialists for people with memory loss across geographical areas.
- Many General Practitioners are not well-informed about dementia, and sometimes do not refer people to appropriate services where they present with a memory-related issue. Many GPs assume ageing automatically involves memory loss and confusion. The NSW HACC Issues Forum heard several examples of this occurring. This response from GPs continues despite ongoing strategies in the past to raise awareness about dementia amongst health professionals.
- GPs have limited opportunities to monitor peoples' cognitive capacity on an ongoing basis. GP consultation times are brief, and often do not give GPs the opportunity to pick up on signs and symptoms of dementia. People experiencing memory loss, confusion or behavioural change may be hesitant to report these experiences to their GP, or may mask these symptoms during consultations. Symptoms of dementia can thus go medically undetected for quite some time.
- Costs associated with accessing health care, including fees, transport, accommodation, tests and medical imaging, and foregone income (for those who are employed). These can be quite considerable for people living in rural and regional areas, who may need to travel long distances to attend appointments or undergo procedures. Diagnosis of dementia also often involves multiple tests, appointments, and may require the person to seek a second opinion. These costs can add up to considerable sums.
- Stigma amongst the family of a person with dementia, which may limit their ability to seek diagnosis and intervention.
- Lack of awareness in the community, leading to poor information being passed on to people seeking support. E.g. religious and community leaders may be the first point of contact for a person concerned about their memory, but these leaders are not likely to have useful and correct information about a person's options.
- Specific roles in the general community, e.g. police, businesses, banks, may be working with people with dementia but they tend to have poor information and strategies for dealing with dementia. Additional resources to inform the public, and specific industries, would support people with dementia to go about their everyday lives more effectively.

The NSW HACC Issues Forum considers resourcing the primary barrier to more effectively addressing dementia in the community. A coherent policy framework needs to underpin resourcing, and policy should be based on the support needs in the community. The *National Framework for Action on Dementia 2006-2010* is due for review in 2012. Any revised plan or framework for dementia support in Australia needs to involve a commitment of resources towards the aims of the plan or framework.

Due to the existing failures in the health system at addressing needs for early diagnosis and intervention, the NSW HACC Issues Forum recommends further

resourcing towards non-clinical support for people concerned about their memory, and who may be experiencing dementia. Dementia and Memory Community Centres, such as that operating in the Hunter region in NSW, offer an excellent model for providing people with dementia and carers better support in accessing the diagnosis and interventions they may need. They also serve as a basis for peer support through support groups, and can facilitate community education on issues such as advance care planning and family support¹. They can assist to build critical support networks for the person with dementia, to maintain and improve their social connectedness and prevent isolation.

The Hunter Dementia and Memory Centre facilitated the development of a Clinical Pathway for assessing people under 65 years of age for dementia. The Clinical Pathway maps the clinical stages for the person from the point of initial consultation with the GP, through to neurological testing and referral to specialists. This Pathway was agreed as a protocol for clinicians and signed by the Medicare Local. This protocol, unique in NSW, could be a model for future practice in dementia diagnosis and care. It outlines clearly for GPs the steps they can take to address suspected cognitive impairment and where to assess for dementia. Responsibility for facilitating, managing and updating such protocols should be placed with agencies that have the capacity to undertake these tasks. Dementia and Memory Community Centres could liaise with Medicare Locals and Health Networks to establish these protocols.

Awareness-raising in the community about dementia should be flexible and allow communities to adapt information to their own circumstances. Formats such as theatre, community television, and community art projects should be considered for raising awareness about dementia in Australia's diverse communities. Support for such initiatives could be delivered through Dementia and Memory Community Centres.

Awareness raising should emphasise that:

- Dementia is not a condition that only affects older people. That is, it is not inevitable in *all* older people, and it is not a condition that *only* older people develop. Some older people do not develop dementia; some younger people do develop dementia.
- Dementia is caused by illness; it can be fatal.
- Dementia can be managed. Resources are available for caring for and supporting people with dementia and their carers.

Recommendations

2. That the Australian Government develop a national action plan for dementia support, which includes a substantial investment of new funds.
3. That dementia be promoted to a National Health Priority.
4. That the Australian Government establish and resource community-based dementia resource centres with a physical presence where people with memory loss, people with dementia, and carers and families can seek information and support with obtaining diagnosis and early intervention.

¹ See Alzheimer's Australia (2012) *What prevents people with dementia making plans for their future?* Discussion paper 4, March 2012, North Ryde, Sydney, available at: <http://www.fightdementia.org.au/common/files/NSW/20120328-REP-DiscussionPaper4.pdf> (last accessed: 11/05/2012).

5. That the Australian Government provide resources for flexible community awareness raising programs which present information about dementia in a variety of modes that are appropriate for a variety of communities.

Younger Onset Dementia

Early intervention and diagnosis is particularly important for people with younger onset dementia². Younger onset dementia can be considerably disruptive for a person's life, as dementia is less common in younger people and is generally associated with older age. However, dementia has been diagnosed in people in their early 30s³.

Misdiagnosis of younger onset dementia is common. The NSW HACC Issues Forum heard about many cases of people with younger onset dementia receiving initial diagnoses of depression and prescription of antidepressant medication. In many cases it takes several years to obtain a diagnosis. Because younger onset dementia involves a greater variety of types of dementia, diagnosis can be complex, involving multiple tests and consultations.

Stigma and lack of understanding about dementia are compounded for younger people with dementia, which can lead people to miss opportunities to make advance legal, financial, health and care arrangements for times where they may not fully participate in those decisions. This can lead to increasing workloads and stress placed on carers who then go on to seek intervention when they are in crisis.

People with younger onset dementia can be at a very different life stage than older people with dementia. They may be in full-time employment, with caring responsibilities for children, may be physically fit and active, and have a number of interests. As support for dementia is mostly funded and provided in the aged care sector, people with younger onset dementia do not necessarily identify with needing the types of care or support available for people with dementia.

Furthermore, lack of understanding of dementia can have very different life outcomes for people with younger onset dementia. People with younger onset dementia and their carers may not have the financial means to leave paid employment. A person may have their performance managed or may lose their job before a formal diagnosis is obtained. Dementia can therefore lead to considerable financial hardship. Carers may need to suspend employment in mid-career, and may find their skills are not up-to-date to re-enter the full-time workforce after the care situation for the person with dementia changes.

This can be compounded by family problems, with partners/spouses and children of the person with dementia having difficulty adjusting to the changes in their family as a result of dementia. The NSW HACC Issues Forum has heard of relationships breaking down as a result of the behavioural changes associated with dementia.

² Younger onset dementia is defined as dementia occurring before the age of 65 in non-Aboriginal people, and before the age of 50 in Aboriginal and Torres Strait Islander people.

³ Thompson D., (2011), *Service and Support Requirements for People with Younger Onset Dementia and their Families, Literature Review*, SPRC Report 9/11, prepared for Alzheimer's Australia NSW, September 2011, University of New South Wales, Sydney. Available at: http://www.sprc.unsw.edu.au/media/File/1Alzheimers_YOD_lit_rev_FINAL_DT_Oct11final.pdf (last accessed: 13/04/2012).

Support for people with younger onset dementia should take these differences into account. Support with financial and legal matters may be needed for younger people, as well as relationship and family issues. Support needs to be flexible to account for the diversity of the population of people with younger onset dementia.

Recommendations

6. That the Australian Government invest in new models of care for younger people with dementia, including individualised funding models for supporting people with younger onset dementia to allow flexible delivery of support.
7. That the Australian Government integrate information about younger onset dementia into awareness-raising campaigns about dementia.

The NSW HACC Issues Forum looks forward to the prompt public release of the final report to inform the sector and to honour the participation of the respondents.

Should clarifications or further information be required, please contact Rashmi Kumar, Senior Policy Officer with NCOSS at _____ or (02) 9211 2599

Yours sincerely

Alison Peters
Director, Council of Social Service of NSW (NCOSS)
On behalf of the NSW HACC Issues Forum