

AGED CARE ASSOCIATION AUSTRALIA LTD



Level 1
 25 Napier Close
 Deakin ACT 2600
 PO Box 335
 Curtin ACT 2605

T: 02-6285 2615
 F: 02-6281 5277

office@agedcareassociation.com.au
www.agedcareassociation.com.au

ACN 053 998 860
 ABN 81 053 998 860

10 May 2012

Standing Committee on Health & Ageing
 PO Box 6021
 Parliament House
 Canberra ACT 2600

E: haa.reps@aph.gov.au

To Whom It May Concern,

RE: Submission to the House of Representative’s Committee on Dementia: *Early Diagnosis and Intervention*

Thank you for the opportunity to provide a submission to the above enquiry and also for the extension of time.

ACAA have consulted with aged care providers across Australia and this submission provides a summary of the key issues identified and some recommended actions for the Committee to consider.

1. A dementia public awareness campaign, with a positive difference

Recent research and reporting regarding the physical, financial and emotional impacts of dementia on individuals, families and communities has left no room for doubt about the seriousness of the disease and the criticality of addressing dementia issues now to prevent a future global crisis.

Whilst a statistic such as ‘a new case of dementia arises globally every 4 seconds¹ raises the dementia crisis profile, it does little to allay the anxiety of those impacted, encourage an early dementia diagnosis, or address the stigma and misinformation still surrounding the disease.

An early diagnosis, supported by multi-disciplinary dementia care teams – (comprising doctors, specialists, counsellors, family members, communities etc.) could see an:

- Improved understanding of the disease for all those impacted
- Improved levels of involvement in advanced care planning, particularly for those individuals/families uncertain what the future holds post diagnosis
- Improved approach toward management and self-determination, rather than just treatment

2. A broad approach to Workforce Skilling

¹ World Health Organization 2012, Dementia: a public health priority, WHO Press, Geneva, Switzerland

State Offices
NSW
 PO Box 7
 Strawberry Hills NSW 2012
 T: 02-9212 6922
 F: 02-9212 3488
 E: admin@acaansw.com.au
 W: www.acaansw.com.au

QLD
 PO Box 995
 Indooroopilly QLD 4068
 T: 07-3725 5555
 F: 07-3715 8166
 E: acqi@acqi.org.au
 W: www.acqi.org.au

SA
 Unit 5, 259 Glen Osmond Road
 Frewville SA 5063
 T: 08-8338 6500
 F: 08-8338 6511
 E: executive@acaasa.com.au
 W: www.acaasa.com.au

TAS
 PO Box 208
 Claremont TAS 7011
 T: 03-6249 7090
 F: 03-6249 7092
 E: smithgardens@bigpond.com

VIC
 Level 7, 71 Queens Road
 Melbourne VIC 3004
 T: 03-9805 9400
 F: 03-9805 9455
 E: info@accv.com.au
 W: www.accv.com.au

WA
 Suite 6, 11 Richardson Street
 South Perth WA 6151
 T: 08-9474 9200
 F: 08-9474 9300
 E: amarcher@acaawa.com.au
 W: www.acaawa.com.au

With new insights into dementia occurring every day, the aged care workforce requires contemporary and advanced levels of training and skill development subsidised by Government. Initiatives to date have largely focused on delivering a Certificate 3 skill level to direct care workers. The professional development needs of the entire aged care workforce from managers to clinicians, care workers and ancillary staff need to be catered for by Government subsidised training.

Early diagnosis is a critical element at a local community level. Primary care providers including GPs, practice nurses and community health workers need a basic level of awareness raising about early signs of dementia and the distinctions in the context of differential diagnosis. The federal government's aged care reform package cites this as a skills or competency gap and is providing additional resources to target early diagnosis.

Family carers are an unpaid component of the dementia workforce and education about dementia, its impacts and management strategies for various symptoms and behaviours would all be beneficial.

Ongoing dementia training and education programs, supported by committed leadership, enable:

- Improved dementia management, care and support for individuals and families accessing aged care services
- Improved collaboration, coordination and cooperation between staff at all levels involved in aged care
- Improved staff satisfaction and competency in supporting the growing number of people with dementia

3. Appropriate Funding and Service Availability to support a continuum of care

Ensuring multi-disciplinary dementia care team members (irrespective of roles) are well trained, educated and/or informed will require a commitment to significant and ongoing funding. Funding and financial support arrangements/administration will need to be flexible in responding to the varying degrees of support required to ensure a continuum of care. The proposed funding enhancements for residential care and the new dementia supplement to apply across all levels of home care packages as outlined in the Living Longer Living Better aged care reform package are welcome developments.

Local services and care and geographical stability have been identified as success factors for people with dementia, so being able to receive care and intervention programs in familiar environments is preferred for both people with dementia and their carers.

Families of people with dementia have a clear priority to improve basic care services, as stated in Alzheimer's Australia's report 'Effective Consumer Engagement in the Aged Care Reform Process', released recently. Better results are achieved when families can choose services and activities relevant to their loved one, and the extension of Consumer Directed Care in community care will improve outcomes. Age should not be the only determinant of service eligibility.

An increased funding commitment should provide:

- Appropriate levels of care and support to people with dementia in residential care or accessing community care
- Appropriate dementia expertise to be sought by aged care providers when required
- Greater continuity in the care and living arrangements of people with dementia

4. Identification and support of early onset dementia and for culturally diverse and marginalised communities

Dementia is also emerging as a condition in younger age-groups and those from Culturally and Linguistically Diverse (CALD) backgrounds. In advocating for early diagnosis and a continuum of care supported by multi-disciplinary teams, it is important to identify and support those population segments currently at risk of becoming marginalised or forgotten. In doing so it is important to remember that many languages do not have a word for 'dementia', with dementia behaviours understood to be a normal part of the ageing process. More research is therefore required into the perceptions and attitudes of CALD communities regarding dementia, early onset dementia, community residential care, barriers to diagnostic and treatment services and the roles of family and religious leaders.

Information about dementia for CALD older people and their families also needs to be delivered in places of familiarity and comfort, such as places of worship or gathering, offering interpreter services, support from community leaders, and sufficient time for comprehension and questions.

Ongoing dementia training for CALD community and residential care staff needs to also consider the organisation of appropriate activities for CALD older people in dementia units, residential care and/or accessing community care.

There is also a need for research to consider whether the premature ageing evident in some population subgroups, such as Indigenous Australians, Refugees and people who have been chronically homeless, is also giving rise to a concentration of earlier onset dementia. The current split in funding and administration responsibility for aged care services (not progressing at this point in Victoria and Western Australia) to people 65 years and over (50 years and over for Indigenous Australians) to the Commonwealth Government and the State Government assuming full responsibility for supporting people under 65 years, has the potential for younger people and their families to struggle to receive timely and adequate services and support. The role of the Aged Care Assessment Teams (ACAS in Victoria) needs to be defined and appropriate consistent assessment tools developed with reference to how younger people with early onset dementia are appropriately assessed and linked into available services.

In Queensland, the Home and Community Care (HACC) Program has successfully contracted Ozcare to operate a state-wide Dementia Advisory and Support Service to provide support and advice to people with dementia across all age spectrums and to community service providers.

Identifying and supporting marginalised people living with dementia and respecting their decisions and individual backgrounds may well require a more complex approach to multi-disciplinary teams, potentially requiring ethical, medical and legal perspectives. A focus on addressing this gap in dementia care could see:

- Improved overall health outcomes resulting from multi-disciplinary care team support
- Improved understanding of dementia issues facing sufferers from socially excluded groups

5. Interfaces with the health system

Better connections between General Practitioners (GPs) and emergency department triage staff are essential, as are pathways for two-way referral and communication. Similarly, two-way communication between GPs and medical specialists will help to address current gaps reported by families. Aged Care Assessment Services and Teams (ACAS/ACAT) vary across regions and their clinical priorities need to better match the expressed needs of families and carers and people with dementia.

Variations in the provision of primary, secondary and tertiary health care vary considerably across Australia, and strategies for addressing the timely availability of skilled dementia professionals in rural, remote and regional areas are required. The case study below is representative of the experiences of many rural, regional, remote aged care providers across Australia.

A Regional Victoria Case Study

“We run numerous dementia support and carer support programs both state and federally funded. We see that there are many advantages in accessing supports early in the dementia process for the carer and the person with dementia. The advantages are it decreases the social isolation that the illness can cause, improves the prognosis with more treatment and management options available to people who are engaged in supports and services, reduces carer burn out and it enables better acceptance of supports when they are required in the later stages.

Unfortunately we do not see enough early intervention in our region. The nearest Geriatrician is more than 2 hours away and we have no access to a geriatrician except through the Cognitive, Dementia and Memory Service (CDAMS)² clinic which visits our

² Cognitive, Dementia and Memory Service (CDAMS) clinics across Victoria were established in response to identified service sector deficits in the diagnosis and management of cognitive difficulties and early stage dementia. CDAMS clinics were established as a component of a comprehensive sub-acute service system as an accessible, multidisciplinary, specialist service providing early diagnosis, advice, support and referral for people with cognitive difficulties causing confusion, memory loss or thinking problems. (Department of Health website, accessed 27 April 2012).

area once per month. Diagnosis is often not possible until the later stages of the illness when symptoms are obvious. This has an impact on our ability to engage people with dementia and their families in the early stages. Our experience is that we do not see people with dementia in our programs until the illness has progressed to a level that the carer or family are in crisis. This often makes engagement difficult and emotive, and our involvement can often be short lived in some community programs, as the client will quickly deteriorate beyond the level of support a program can provide, and more intrusive supports are required. These are often not available locally”.

Once again, thank you for the opportunity to submit to this enquiry.

Yours sincerely

Rod Young
CEO
ACAA