

Submission No. 082

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(Dementia)

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**SUBMISSION TO
HOUSE STANDING COMMITTEE ON HEALTH AND AGEING
INQUIRY INTO
DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION**

Prepared by National Policy Office

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TABLE OF CONTENTS

INTRODUCTION	1
ISSUES	2
Improving awareness and communication	2
Planning for the Future	3
Improving diagnosis	4
CONCLUSION AND RECOMMENDATIONS	5

INTRODUCTION

COTA Australia is the national policy arm of the eight State and Territory Councils on the Ageing (COTA) in NSW, Queensland, Tasmania, South Australia, Victoria, Western Australia, ACT and the Northern Territory.

COTA Australia has a focus on national policy issues from the perspective of older people as citizens and consumers and seeks to promote, improve and protect the circumstances and wellbeing of older people in Australia.

COTA Australia welcomes this Inquiry as the issues around diagnosis and then support for people with dementia is an issue of great importance to older people and is often raised in forums hosted by COTAs around the country. The provision of adequate dementia care was raised in the 'Conversations on Ageing conducted by the Minister for Ageing in 2011/12 with people raising concerns about the adequacy of community care, the need for more research and better treatments and some very specific issues raised with regard to younger people with dementia.

COTA is pleased that the terms of reference for this Inquiry essentially mirror the benefits of timely diagnosis to both the person with dementia and their families and carers as identified by consumers. These benefits include:

- better understanding of the cause of the symptoms and the progression of the disease;
- timely access to potentially beneficial medications to help with some of the symptoms of dementia;
- timely access to information, counselling and support services as well as the opportunity to build new support networks;
- time to put in place plans for legal, financial and future medical care including enduring powers of attorney and advanced health directives; and
- time to make important choices around family, employment, accommodation and social relationships before the dementia progresses.

All of these enable people to make choices and decisions that optimise the quality of their lives and to remain independent, with appropriate supports, for as long as possible.

Despite there being this acceptance of the benefits of timely diagnosis the majority of people with dementia live and die with the condition without receiving diagnosis at all and in Australia the average time from symptoms appearing to diagnosis is 3.1 years which can hardly be considered timely¹.

The Living Longer. Living Better. package of aged care reform addresses some of these issues and COTA joins Alzheimer's Australia in welcoming the dementia package within those reforms. We welcome the commitment in the package to reduce the period of time from symptom onset to diagnosis and believe that our recommendations will make a positive contribution to achieving that objective.

¹ Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189, 487-9.

We support the submission and recommendations from Alzheimer's Australia to the Inquiry. Our submission is informed by the input from our members and the broader older population and focuses on areas for improvement.

ISSUES

Improving awareness and communication on dementia and dementia-related services in the community.

It is clear that there is still a degree of stigma attached to a diagnosis of dementia with people not wanting to talk about it or think that it might be the cause of their symptom. Often people are desperate to attribute cognitive decline and behavioural changes to almost anything other than dementia because they fear the disease and what it may mean both for themselves and their families.

What is also clear is that for many people, and especially for older people, the symptoms of dementia, are just attributed to the ageing process and therefore assessment and assistance are not sought. It often takes an external person to raise the idea that what is happening is not "normal ageing" before people seek assistance. Or they face a crisis or accident that brings the issue to the surface when it can no longer be ignored. For younger people with early onset dementia this is clearly more of an issue as there is not even the idea of age as a prompt to consider dementia as a diagnosis.

There is a lack of broader community understanding of what dementia is, how the symptoms manifest themselves and how the disease progresses. This means that people do not raise the possibility with their health professionals and are not well placed to push the idea if it is dismissed initially by the health professionals. Clearly we need to improve people's awareness of how dementia manifests itself so they can be empowered in as health consumers to ask the right questions, seek the best interventions and make informed choices about their health care and their lives more generally.

To address all of these issues COTA joins Alzheimer's Australia in calling for a comprehensive national awareness campaign that increases community understanding of dementia, how it manifests itself and what supports are available. Alzheimer's Australia is best placed to lead such a campaign but there would need to be provision for them to work with other groups to ensure it addresses the needs of specific groups including Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds and the lesbian, gay, bisexual, transgender and intersex communities.

Such a campaign would reduce the stigma of dementia and be better accepted in the community. This should reduce social isolation for people with dementia and their carers, and so would make a big difference to their quality of life. As one carer said "Norm was a keen bowler but after his diagnosis his bowling club friends were a bit scared of how he might behave. If they only understood his condition I feel sure they would be more supportive"².

People tell us that the initial diagnosis is often a shock and that then they have no idea what supports are available and how to access them. There is also a need for ongoing information and support so people can feel that they understand how the disease is progressing, what they might

² Carer in NSW.

expect to happen next and to develop strategies that allow them to cope with the required adjustments to their lives.

Again we support Alzheimer's Australia in their call for a key dementia worker program to provide people with dementia and their families and carers with access to somebody to support them through these major life changes they will have to make. People tell us the information can be overwhelming and that they simply don't know where to start. Not only do they have to contend with complex medical information but they need to look at planning for future events and deal with major lifestyle changes. Whilst many are happy to access information on the internet and through written information most people say they would like somebody who can help them interpret that information who knows their situation and so can make it relevant for them.

Planning for the Future

People with dementia and their carers need to plan for the future and this includes organising financial and legal affairs as well as thinking about future health care choices. Older people have told us repeatedly they want to ensure that their wishes with regard to treatment, particularly at the end of their lives, are respected. They see the introduction of Advanced Care Directives (ACDs) as critical part of that process as it gives them the opportunity to record their wishes.

Early diagnosis is critical if people are to be able to plan for their own future as they need to have the cognitive capacity to make decisions such as drawing up an enduring power of attorney, making a will or writing their own advanced health care directive.

COTA offices around the country get a number of enquiries from people about how to get an enduring power of attorney, how to put in place an advanced health directive and often these enquiries are from family members of people with dementia. Unfortunately a number of these are for people who have missed the opportunity because the dementia is too far advanced.

Carers struggle with legal and administrative ambiguities around responsibility, advocacy and power of attorney. They frequently are unable to act for the person with dementia because they are not recognised as the responsible person. This also comes up in the health care arena in terms of who is considered the statutory health decision maker in the absence of any legal documentation.

The community awareness campaign and the key worker initiatives would both help to address this issue. The campaign should actively promote advanced health care plan or directives, and the need to put in place powers of attorney.

COTA has raised with the Senate Inquiry into Palliative Care and in other places the need for a nationally consistent approach to advanced health care directives and believes this Inquiry should also look at this.

The key workers could help people think about what actions they need to take and help them through the process. For health care directives they could work in concert with the Respecting Patient Choices Facilitators to help people make the important decision about what sort of treatment they do and do not want in the future.

However COTA offices report people seeking assistance with meeting the costs of preparing such instruments, particularly for power of attorney. Legal Aid in some jurisdictions provides some assistance as do the Public Trustees, Law Societies and there are some lawyers who provide some pro bono assistance but it is patchy and hard to find.

COTA is recommending that there should be funding to assist people to put in place powers of attorney and advanced health directives. Before deciding how such an initiative could be implemented it would be helpful to get a clearer picture of the extent of such assistance already available. The additional funding could either be given to organisations already providing assistance or through a grants process with organisations able to tender to provide the service.

Improving diagnosis of dementia, particularly in primary care

There is plenty of evidence that GPs and other primary health care workers are not diagnosing dementia or not communicating it even when they have made one. The reasons for this include

- lack of education and training around dementia - this is often highlighted by GPs ;
- lack of suitable diagnostic instruments that GPs have confidence in using;
- lack of time in the current GP consultation model to undertake a thorough assessment;
- an assumption that dementia is an inevitable part of ageing;
- an assumption that nothing can be done about dementia so there is no point diagnosing it;
- lack of knowledge of supports and services for people with dementia
- lack of clear guidelines and referral pathways.³

It is clear that GPs and other primary health care professionals need more education about dementia, including around how it is not an inevitable part of ageing and around what treatments are available to improve the lives of people with dementia. This is all disappointing as early diagnosis combined with information and support allows time for planning, which facilitates longer independence.

The awareness campaign already discussed could in part meet this need and educate doctors at the same time as the rest of the community. They would then have a better understanding of the benefits to the individual and their families and carers of an early diagnosis.

Doctors also need more professional education and training, both during their initial training and on an ongoing basis. There needs to be a better system of dementia education and professional development for GPs and Practice Nurses. This would assist with ensuring GPs and other primary health care workers have an up to date knowledge of development in both medication regimes and other treatment and management ideas that could be beneficial to their dementia patients.

There is also a need to provide an incentive to primary care to undertake more thorough assessments and to provide better ongoing support for people with dementia. Neither of these fit comfortably into the time for a standard consultation and so there is a need to look at different ways to remunerate GPs to undertake this work and to encourage them to make better use of practice nurses, nurse practitioners and specialist dementia care nurses to provide a more holistic approach to the person's care. This could be done by refining MBS Item numbers or creating specific incentive payment for the practices and making better use of existing health assessment process and payments.

One of the key issues that have arisen from our consultations around this issue is that people feel health professionals, especially GPs, ignore loved ones/primary carers' concerns and devalue their observations. The following story illustrates the point.

³ List taken from Alzheimer's Australia submission to Inquiry

“I went with Mum to her GP and I told the GP that I was worried that Mum’s memory seemed to be deteriorating. The GP turned to Mum and said ‘Margaret how is your memory?’ To which Mum replied ‘Never better-it’s better than hers’. The doctor turned to me and said “I don’t think there is anything to worry about’. He did not ask why I thought Mum’s memory was fading and I felt belittled and irrelevant. It certainly made me think again before I raised similar concerns”⁴

Clearly families and carers who spend a lot of time with people are well placed to provide information on the person’s behaviours and to notice changes in those patterns. The work done by Kemp et al showed family/carer informants to be accurate in their assessment in 60 per cent of cases⁵. This shows that they are often correct and their information should never be discounted. We also believe that with improved understanding of dementia as a result of the awareness campaign informal reports would become more accurate. Even if it is only used as the trigger for a more thorough assessment it has a place in the process. The suggested education and professional development should include use of informal reports and ways to improve the collection of such information.

CONCLUSION AND RECOMMENDATIONS

There is a growing acceptance that people with dementia benefit in so many ways from early diagnosis and intervention. However it is also clear that the degree to which people can access an early diagnosis and then receive appropriate interventions is very patchy and is determined to a large extent by the preferences of the health professionals they see or where they live. This is not good enough and our package of recommendations is designed to give people more confidence that they will get an early diagnosis and will be able to access the supports they need to help them adjust their lives appropriately.

COTA recommends:

1. Funding for a comprehensive national community awareness and education campaign
2. Additional funding for more targeted information and awareness campaigns for specific groups within the community including Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse background and members of the lesbian, gay, bisexual, transgender and intersex communities.
3. Development of a program of Key Dementia Workers to provide ongoing information and support to help people navigate the complex service system and deal with life changes
4. Funding for assistance with preparing powers of attorney, advanced health care directives and other future planning documents that give individuals and their carers more choice and control over what happens in the future.
5. Development of a remuneration and incentive package to encourage better assessment for dementia in primary care
6. More emphasis put on dementia diagnosis and management in ongoing education and professional development packages for GPs and practice nurses

COTA would welcome the opportunity to discuss these issues with the Committee and looks forward to seeing the outcomes of the Inquiry later this year.

⁴ Provided by COTA member- names changed.

⁵ N M Kemp, H Brodaty, D Pond, G Luscombe; *Diagnosing Dementia in Primary Care: the Accuracy of Informant Reports*, Alzheimer Disease and Associated Disorders, July/Sept 2002, Vol 16 Issue 3 pp171-176