



Brotherhood  
of St Laurence

Working for an Australia free of poverty

# Submission to the Inquiry into Dementia: Early Diagnosis and Intervention

Brotherhood of St Laurence

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## Summary

With the rapid increase in prevalence of dementia internationally and in Australia, there is a need to identify issues for people living with dementia and their carers. There is a high economic impact on families, carers and communities, and an associated stigma and social exclusion. A changed approach is required from government, providers of care and the community if we are to enhance dementia care in order to improve the social wellbeing and quality of life of those living with dementia and their carers.

There needs to be greater awareness raising of dementia and advocacy for those living with dementia, based on principles of inclusion, integrity and equity. A lack of understanding of dementia contributes to fears and stigmatisation and may lead to subsequent social isolation and exclusion and to delays in seeking diagnosis and support.

People with dementia and their families and carers face significant financial impact from the cost of health and social care and from the reduction or loss of income due to their inability to retain or gain employment. Education programs are required for employers, employees and the public at large to increase understanding and recognition of the rights of people with dementia and reduce discriminatory practices. Fundamental to this is recognition of the capacity of people with dementia and acknowledgement that in the early stages of dementia people have the capacity to make decisions about their future. Education and support regarding these rights are also required for carers and professionals.

Greater awareness and understanding of dementia across all levels of society can improve the quality of life of people with dementia and their carers. Governments need to resource public awareness campaigns and ensure key stakeholders are involved. However, awareness raising needs to be relevant to the context and the audience. Support for carers needs to include information to aid understanding, skills to assist in caring, respite to enable engagement in other activities, and financial support.

The Brotherhood of St Laurence (BSL) has approached the terms of reference of the inquiry from this perspective. Priority areas advanced are:

- the raising of awareness of dementia among professionals, community groups, providers of care, employers and employees, and the public at large
- timely diagnosis
- development of a skilled care workforce with training in dementia care
- carer support opportunities
- advanced care planning.

BSL has also provided in this submission examples of its programs and models which deal with early intervention and support for people with dementia and their carers.

# 1 Introduction

Thank you for the opportunity to make a submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention.

## The Brotherhood of St Laurence

The Brotherhood of St Laurence (BSL) is a large not-for-profit organisation whose mission is to create an inclusive, compassionate, just, prosperous and sustainable society. In promoting social inclusion, the BSL takes a life-course approach to research, policy and service delivery, with special emphasis of four life transitions—the early years, from school to work, in and out of work and retirement and ageing.

## The context

The Australia Government, through its social inclusion agenda, seeks to reduce disadvantage, increase social, civic, and economic participation and develop for all Australians a greater voice and greater responsibility. The foundation of aged care policy needs to shift from addressing ageing as a deficit and focus instead on people's capabilities. This will effectively shift the ground from a dependency model to a model where older people as adults exercise their full complement of choices and rights. The capabilities framework assists the BSL to deliver a suite of community and residential programs which enables people to remain active members of their community and of their own lives.

The prevalence of dementia is growing and will increase from around 257,000 people in 2010 to just over 981,000 in 2050, with the growth rate expected to peak between 2021 and 2030 as the baby boomers age. This submission draws on our experience in delivering programs to support people with dementia and their carers from early on set to end stage dementia. The provision of quality dementia care delivered by the BSL is based on the belief that each person and situation is unique, and the individual and their informal carer deserve to be treated with respect and dignity. The experiences, emotions, values, beliefs, social, intellectual, spiritual and cultural background of each person experiencing dementia must be acknowledged and valued.

The BSL has been proactive in response to people with dementia and their carers, delivering a range of innovative services and approaches as these people travel along the dementia pathway. Dementia care initiatives which the BSL is currently delivering or developing include:

- Caring For Carers Project
- Dementia Lending Library (including materials relevant to individuals of CALD and ATSI background)
- Memory Lane Cafes in partnership with Commonwealth Respite & Care Links Centre (CR&CC), Benetas and Alzheimer's Association Victoria (AAV)
- Cognitive Stimulation Therapy (currently being trialled in one of our residential services)
- Dementia Knowledge Management System
- Short Break Stay, a program that provides short-term community-based residential care to people with advanced dementia in order to provide respite to their carers.

## 2 Response to terms of reference

### **How early diagnosis and intervention can improve quality of life and assist people with dementia to remain independent for as long as possible**

The Brotherhood of St Laurence is well known for its social inclusive policy platform that has underpinned much of the organisation's work in dementia care over the past eight years. People with dementia and their carers are some of the most marginalised of our citizens. Both groups are excluded and need social inclusion to be considered in any future policies that involve inclusive growth.

When thinking about dementia, particularly early onset dementia, social inclusion is an important concept in relation to people maintaining their independence, status and rights to the many benefits of citizenship. As dementia has become more common, a social inclusion approach is required to ensure that people with dementia and their carers are not excluded from productive lives, including engaging in all aspects of social, civic, learning and work participation opportunities.

A consequence of lack of understanding in the workplace is stigmatisation and the inability for the person with early onset dementia or first stage dementia to maintain employment. This has an impact not only on the person's economic and social wellbeing but also on society which loses the wealth of human knowledge and resources which the person contributed. Respecting and acknowledging people's knowledge and experience is important in maintaining an inclusive society. Flexible working arrangements for working carers would also assist the carer to remain in employment and also continue in the caring role. The early diagnosis of dementia could assist in clarifying the grounds for, and the implementation, of these arrangements.

Research has shown that early diagnosis and intervention plays a key role in improving people's quality of life and assists them to remain independent for as long as possible. What is unfortunate is that people with dementia and their carers are not gaining the benefits they should be through early diagnosis.

BSL carers report that they have experienced a delay in diagnosis of up to six years, despite the carers reporting subtle changes in their family member to their GP. Alzheimer's Australia reports similar findings from carers, with Aged Care Assessment Teams (ACAT) and GPs coming under criticism for delayed diagnosis. Carers felt they were not listened to and the professional relied solely on a single occasion assessment tool rather than the wealth of intimate knowledge the carer had about the person for whom they were caring.

During consultations with Alzheimer's Australia commissioned by the Department of Health and Ageing, carers reported that gaining a diagnosis for early onset dementia (YOD) was even more difficult, as GPs were reluctant to label a younger person with dementia. Alzheimer's Australia went on to report that carers felt disadvantaged by their caring responsibilities which had an impact on their capacity for either gaining or maintaining employment which affected their lifetime earnings. These same carers supported the concept of a superannuation component in the Carer Payment, given the greater impact on lifetime earnings for a carer of a family member with YOD.

Once a diagnosis was made, carers reported that GPs were no longer interested in providing care to the person with dementia. This is supported by BSL carers who reported that after the diagnosis they felt their GP, although 'nice', was ill-equipped to provide the ongoing management. This lack of access to an interested primary health professional further disadvantaged people with dementia

and their carers by creating barriers to treatment and supports moving along the dementia continuum (Alzheimer's Australia 2011).

The Alzheimer's Australia consultations revealed the overwhelming view by consumers that the aged care system is not working well for people with dementia and delays in diagnosis further exacerbate barriers to support and services. The report states that for a person with dementia the journey needs to start with a timely diagnosis, referral to support services, properly resourced assessment services and a link worker to provide guidance where needed (Alzheimer's Australia 2011).

BSL has developed a dementia model of care called 'The Dementia Care Pathway'. This model outlines a pathway to assist clients/carers and professionals to negotiate the journey through the dementia experience and is supported by a Dementia Care Consultant (DCC) and Dementia Care Coordinator (DCCo) who provide expertise, consultancy, advice and support.

The model represents the progression through the three stages of dementia care through the services available within BSL and in the broader community. It is currently, a tool for all BSL staff to use to assist clients/carers and professionals to recognise changes and the need for current and future planning.

The model allows for an entry point at any stage of dementia, with specific information tailored for each stage. It is a prompt for staff and represents a person-centred approach to dementia care, realising that individual clients and carers will have diverse needs at any stage. BSL is currently exploring a web-based tool based on the model. This will enable clients, carers and professionals to anticipate the planning, support, services and resources that may be needed at critical junctures along the dementia pathway. However, the development of the model has not received funding, which limits our capacity to develop it further and make the tool available to other organisations.

## Recommendations

- Implement a public awareness campaign in relation to working alongside people who either have signs of early onset dementia or have caring responsibilities for a person with dementia.
- Develop and implement an employers/employees support scheme to provide strategies for supporting employers and employees in the workplace in relation to early onset dementia and carers' responsibilities when caring for a person with dementia.
- Implement models of care such as BSL's Model for Dementia Care, which highlights the benefits of early intervention.
- Implement a comprehensive workforce training program in the benefits of early dementia diagnosis, aimed at GPs and GP practice nurses.

### **How early diagnosis and intervention can increase opportunities for continued social engagement and community participation for people with dementia**

As reported by Alzheimer's Australia (2011) consumers emphasised that they wanted to remain at home for as long as possible; and community care was highlighted as a way to achieve this. However, BSL considers that the general population also plays a role in ensuring whether people with dementia remain active members of the community. It is well documented that people with dementia feel stigmatised, experience an immediate identity loss upon diagnosis and may be excluded from their social networks, resulting in isolation.

BSL recommends that, where possible, a restorative approach, emphasising what the person can do as opposed to what they cannot do, be adopted. This is particularly important with early diagnosis, when the person living with dementia is able to continue his/her role in society, including employment, family, social engagement and civic participation, with support. This is counter-intuitive to the system which financially rewards the higher end of care rather than at the stage where a restorative approach can still be considered (Alzheimer's Australia, 2011). As noted by a BSL carer, 'social inclusion opportunities are important for both the person with dementia and their carers'. However many of the carers to whom we spoke reported that their family member has experienced exclusion from their social groups and clubs. This discrimination and exclusion is often a result of people's lack of empathy, understanding and knowledge of dementia. Carers have expressed anger and hurt as a result of this exclusion and have confirmed the negative impact on both the person with dementia and the carer.

BSL considers that it is critical to ensure that social engagement and community participation is offered throughout the dementia pathway. BSL carers reported that upon their family member returning from our specialised dementia day respite there were notable differences in their demeanour. The person became 'more sociable', 'communicated better' and 'engaged in conversation'. One carer reported: 'It's been marvellous, in three weeks I have seen her personality come back, and I feel like I have my wife back'. This comment was supported by other carers with similar experiences.

Many of the BSL carers also mentioned the loss of old friendships. Although they felt saddened by this experience, in some ways they could understand the reason for people 'drifting away'. Carers spoke about needing to develop new friendships with people in similar circumstances to themselves.

Over the last 12 months, the BSL, in partnership with Alzheimer's Australia Victoria (AAV), Commonwealth Respite & Care Link Centre (CR&CC) and Benetas, has established a Memory Lane Cafe in the southern part of the Southern Region of Melbourne. This program is funded by the Department of Health, and one of its aims is to provide short-term support through a social opportunity.

A recent evaluation of the program reported that the cafe provides short-term support in many ways. Guests gain peer-to-peer support from others present at the cafe. Meeting with others provides enormous support in terms of helping them to feel less alone. There is the prospect of meeting people who have similar experiences and can consequently offer genuine empathy and validation. It is this non-professional environment that is crucial in helping people rebuild their sense of community when they have had a 'disconnecting' kind of experience (Alzheimer's Australia Victoria 2011 unpub).

The relaxed atmosphere of the cafe also allows participants to 'chat' with local service providers. This more informal contact with service providers offers easy access to service information and referral. Participants might not feel confident to otherwise make this contact when required, especially when they have had no previous experience of these organisations. Alzheimer's Australia Victoria indicates that clients who like the idea of a cafe as a way of meeting other people often go on to self-refer to their other programs, such as the Living with Memory Loss Program, as they have heard from others at the cafe how beneficial another program has been for them. In this way the cafe provides an introduction to other programs. The case study below outlines how a carer was introduced to Banksia Services, a BSL respite program for carers of people with dementia.

## Case study: Gordon and Pauline

(Reported by the program coordinator. Pseudonyms are used and some details have been changed for privacy reasons)

Pauline is in her early seventies and was tested for Alzheimer's several years ago; however the condition was not diagnosed until twelve months later. Pauline lives with her husband Gordon. They are both self-funded retirees.

Pauline and Gordon have one daughter and one son. Pauline has led an active life, firstly as a teacher and then as the owner and manager of an accommodation business with her husband. She is quiet, loves country music and still enjoys being active by playing tennis and dancing.

Pauline was introduced to Banksia while attending the Memory Cafe with her sister-in-law. Pauline likes to go to the cafe. She is able to get dressed up and always enjoys the company and entertainment.

We met at the cafe. Pauline greeted me with a warm smile, but was a little withdrawn. I noticed she was engaging with those on her table by a nod of her head, smile, clapping to the music. Her sister-in-law asked if she could contact me later about respite care.

We established that Pauline's husband Gordon had been caring for Pauline on his own and his sister was concerned for his wellbeing. She had noticed that Gordon was not playing bowls anymore. She went on to explain that he was not open to respite; she believed he was in denial that he needed a break. She asked if a meeting could be arranged.

Gordon came to the centre and a lengthy discussion revealed what he does for his wife, and how she gets very concerned if he is not around. Pauline can still read and write; however she needs prompting with activities of daily living.

Gordon explained how it took a long time for the initial diagnosis and that it has been very hard for Pauline, himself and his family. He has a grandchild with a chronic illness, so he doesn't like to bother his children. He believes they have enough on their plate. It took him a long time to find the right doctor to assist.

Pauline now attends Banksia every Tuesday and stays for overnight respite on a fortnightly basis. The plan is to increase this to weekly when a bed becomes available and when Gordon is ready. Gordon is now attending bowls every Wednesday and collects Pauline on the way home. Pauline is happy to have a 'ladies night in' while her husband goes to his bowls. Gordon has stated that he did not realise what a difference respite would make.

## Recommendations

- Develop an education package/session to assist community groups to establish 'dementia-friendly settings'. This would include information on how to set up inclusive and supportive environments, both social and physical. Raising awareness of dementia is also part of the solution. In order to ensure that a person with dementia is able to remain an active member of a community group flexible and practical support is required, where support staff work closely with the group to build the capacity of group members, and where possible, dementia champions are identified within the community group.
- Recognise that as people's dementia progresses specialised 'day centres' will be required in order to enable the person with dementia to maintain social engagement and meaningful activities. These centres should be staffed by people who are qualified in dementia care and can develop appropriate activity programs which will provide a stimulating and inclusive environment for the person with dementia and at the same time provide respite for the carer.
- Continue the Memory Lane Cafe Model and expand it to other regions to enable people with dementia and their carers to meet other like minded people and to introduce participants to services.

**How early diagnosis and intervention help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements**

It is well documented that long-term planning, including advanced care, is important in ensuring that the wants and wishes of a person with dementia are respected throughout their transition from early to end stage dementia. There is evidence that advanced care planning is occurring in residential facilities at some level. However, there is an inconsistent approach to advanced care planning in the community, with this occurring too late or not at all for many people with dementia and their carers.

BSL carers have reported that they either had not considered or had not attended to future planning in relation to the quality of life considerations that the person they are caring for would like to have addressed as they lose capacity and their care needs become more intensive and in the hands of others. While carers said they had attended to the legal aspects of long-term care—such as enduring power of attorney (both financial and medical)—they appeared to take the approach that ‘I can make these decisions on your behalf’, rather than asking, ‘How do you want me to make these decisions on your behalf?’ Carers reported living in the moment, attending to day-to-day challenges and crises as they arose rather than having a future-focused approach to the care they are providing.

Alzheimer’s Australia (2011) reports that carers were concerned about the quality of care received at the end of life and there was general agreement that there needed to be more awareness and information about the importance of putting in place an advanced care plan and power of attorney. The Productivity Commission (2010, 2011) recommended that all providers should have access to palliative care services and to staff who are trained in discussing advanced care planning.

The BSL packaged care program works with a range of people with chronic degenerative neurological conditions such as MS, MND or Huntington’s disease. Care managers find that these people and their families do best when interventions are planned from the front end of the disease process and adjusted as required as the disease progresses. Dementia is no different, progressing over a period of years with ever-increasing loss of function. Dementia therefore requires the same level of early advanced care planning. BSL has implemented a specific program designed to facilitate that advanced care planning discussion between carers and the person they are caring for, looking at future needs, wants and wishes as the dementia progresses. The BSL Caring for Carers Program is a ten-month community-based dementia care program providing one-to-one education, information and support to family carers. Preliminary evaluations indicate that the program has assisted carers to identify, reduce and manage symptoms of behaviours which are a major cause of carer stress, burden and depression. It has been shown to be most beneficial when introduced in the early stages of the disease. BSL has been providing the Caring for Carers program for two years through philanthropic donations as no government funding has been available to date.

The program has revealed that there is a definite lack of awareness of the importance of being ‘dementia-ready’ and planning for the progression of the disease over time. This can lead to ‘missing the moment’ when the person with early dementia has the capacity and desire to have real input into their future care, leaving the carer with the added burden of making all the decisions for the person without being sure what they would have wanted.

## Recommendations

- Develop a public awareness campaign about being ‘dementia-ready’ in relation to forward and advanced care planning.

- Build the capacity of a broad range of community services (e.g. returned services clubs, GPs, local government and specialist dementia services) through a comprehensive range of awareness raising and education programs, thereby enabling carers to receive information and education on early and advanced care planning, regardless of their point of entry in the dementia pathway.
- Implement the BSL Caring for Carers program model throughout Australia to enable people with dementia and their carers to discuss together their wants and wishes and plan their future care, and be dementia-ready.

### **How to best deliver awareness and communication on dementia and dementia-related services into the community**

As discussed above, BSL recognises the critical importance of raising awareness across the broad spectrum of our community about dementia and the related dementia support services available. BSL provides this type of information at first contact with people through its central point of intake for all clients and carers, enabling a seamless transition between all services whether provided by BSL or the wider community.

The recent release of the Commonwealth's Living Longer Living Better (2012) aged care reform package refers to building a gateway to aged care services. Interest in a single gateway came out strongly in Alzheimer's Australia (2011) consultations with carers. Carers did, however, voice their concern about how it might work, particularly in rural settings. Once a diagnosis is received, remaining with the same key person was seen as essential to the health and wellbeing of people with dementia and their carers. Systemic barriers to this occurring contributed further to people's frustrations.

With the imminent commencement of a number of Medicare Locals across Australia in July 2012, this is an opportune time to ensure dementia is well and truly on the agenda of all these essential primary health and service coordination incorporated health bodies. Alzheimer's Australia currently delivers excellent education and resources to other professional organisations and community agencies, and to individuals through information and telephone, community seminars and website support. This is dependent on initial contact by the other parties rather than the initiation of Alzheimer's Australia, due to a lack of resources.

Alzheimer's Australia (2011) reported that carers felt an impersonal bureaucratic call centre was not enough: the gateway needed to go many steps forward in order to meet their information and support needs. Carers stated they needed more than just information; they needed support in making decisions, a single case manager or dementia nurse who can support them through their journey from diagnosis to assessment and decisions about residential and community care.

Alzheimer Disease International (2011, p. 20) reports that an increase in memory clinic services (known as cognitive, dementia and memory services in Australia) may contribute to an increase in the early diagnosis of dementia. With a fivefold increase in clinics in the Netherlands, there has been an eightfold increase in new clients and a marked increase in the percentage of all Dutch diagnoses made in such clinics. In Croydon in the United Kingdom, over a two-year period following the opening of a community-based memory clinic, there was an estimated 63 per cent increase in diagnoses, with 77 per cent of people referred to the service in the early stages of dementia.

BSL care managers have expressed frustration on behalf of clients when having to overcome resource constraints or geographical barriers to access specialist memory clinics. Alzheimer's

Disease International recommends that health planners and government pay greater attention to the respective roles of primary care, memory clinics and specialist community services and how they work together.

## Recommendations

- Ensure dementia care is core business for Medicare Locals across Australia as part of their mandate as an essential primary health and service coordination incorporated health body.
- Provide funding to enable an integrated service hub or co-location with other community health services, for the implementation of specialist dementia services such as memory clinics.
- Ensure specialist organisations such as Alzheimer's Australia are adequately resourced to build capacity in community groups through outreach education and information programs. This will result in people located in community settings who are able to provide direct assistance to people with dementia and their carers.

### 3 References

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