Brotherhood of St Laurence
Working for an Australia free of poverty

Submission to the Senate inquiry into

Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

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 affecting the care and management of people living with dementia and behavioural and psychiatric symptoms of dementia (BPSD). There is a high economic impact on families, carers and communities, and an associated stigma and social exclusion. The Brotherhood of St Laurence believes that 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 about dementia and BPSD 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. Education programs are required for medical practitioners, community organisations 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 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 and BPSD among medical practitioners, professionals, community groups, providers of care, and the public at large
- the need for person-centred approaches to assist people with dementia and BPSD and their carers
- the need for specialist dementia staff who provide consultation and assistance in the aged care industry
- alternative carer support opportunities
- alternatives to residential facility respite
- the reduction of chemical and physical restraints in managing dementia and BPSD.

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

1 Introduction

Thank you for the opportunity to make a submission to the Senate Committee’s Care and Management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).

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. 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. A 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.

Dementia has a life-changing impact on the person and their family. The incidence of dementia is growing as our Australian population continues to age. In 2012 it was estimated that 311,000 people in Australia had dementia. By 2050, this number is expected to increase threefold to almost 900,000. Like most people, individuals with dementia prefer to live at home for as long as possible and the intention of community aged care programs is to assist people to achieve that aim. In 2011 it was estimated that 70% of people with dementia were living at home. New data from the AIHW shows that 57,922 CACPs, EACH and EACHD packages were in use across the population in June 2011, an increase of 13% on the previous year. It is predicted that in time 80% of aged care services will be delivered in the community.

The Australian community care sector continues to evolve and improve. Since the Charter of Rights and Responsibilities for Community Care (2009), which sets the standards for service providers and the rights of the consumer, there have been four major policy developments that directly impact the quality of support. These include the Living Longer. Living Better Aged Care Reform, 2012; (in Victoria) the *Carers Recognition Act 2012*; the Community Care Common Standards 2011; and the endorsement of dementia as a National Health Priority Area by federal, state and territory health ministers in 2012.

These factors along with the drive from informed consumers, the community aged care industry members such as BSL, and peak organisations such as Alzheimer’s Australia combine to provide quality support in the community for people with dementia and BPSD (Alzheimer’s Australia Vic. 2012).

This submission draws on our experience in delivering programs to support people, younger and older with dementia and BPSD and their carers from early onset to end stage dementia. The BSL provision of quality dementia care is based on the principle 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 and 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 BPSD and their carers, delivering a range of innovative services as they travel along the dementia pathway. Dementia care initiatives which the BSL is currently delivering or developing include:

- Caring For Carers Program, assistance for informal carers to engage with the person with dementia and understand and manage behaviours
- Dementia Lending Library (including materials relevant to individuals of CALD and ATSI background)
- Memory Lane Cafés in partnership with Commonwealth Respite & Care Links Centre (CR&CC), Benetas and Alzheimer’s Australia Vic (AAV)
- Cognitive Stimulation Therapy (used in our residential services)
- the use of Talking Mats for communication (residential services)
- a Dementia Knowledge Management System
- Short Break Stay, providing 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

(a) The scope and adequacy of the different models of community and residential care for Australians living with dementia and BPSD with particular reference to:

- **Commonwealth-provided support and services**
- **state-provided services and**
- **services provided by the non-government sector**

(b) Resourcing of these models of care

The Brotherhood of St Laurence is well known for its commitment to social inclusion, which has underpinned much of the organisation’s work in dementia care over the past eight years. People with dementia and BPSD and their carers are some of the most marginalised of our citizens. Social inclusion is an important concept when considering the ability of people to maintain their independence, status and rights to the many benefits of citizenship, ensuring that they are not excluded from productive lives, including engaging in all aspects of social, civic, learning and work participation opportunities. Unfortunately, people with dementia and their carers are not all gaining the benefits they should be through timely intervention for dementia and BPSD.

Ensuring timely intervention

General practitioners are most people’s link with the primary health system. It is therefore essential that GPs be educated and made aware of the resources available within their communities to assist their patients. Medicare Locals are well under way and are in a unique position to encourage GPs to increase their knowledge of local resources to provide their patients with timely supports and services. Medicare Locals are proposed to act as a conduit between primary health, acute health and aged care. While some of the changes implemented by the Living Longer, Living Better aged care reform, such as the Aged Care Gateway, will help people with dementia and BPSD and their carers to investigate what supports and interventions are available, they will not address GPs' lack of knowledge about resources and strategies to assist.

Alzheimer's Australia consultations (2011) revealed the overwhelming view of consumers that the aged care system is not working well for people with dementia and BPSD and delays in diagnosis exacerbate barriers to treatment and supports moving along the dementia continuum. Their report states that for a person with dementia and their carers, the journey needs to start with a timely diagnosis, properly resourced assessment services, specialist interventionist support services and a link worker to provide guidance where needed (Alzheimer's Australia 2011).

Brodaty, Draper and Low (2003) provide direction on how services can be planned for people with BPSD. They suggest a model which divides people with BPSD into seven tiers in ascending order of symptom severity and decreasing levels of prevalence, from adults with no dementia (tier 1) to the most acute BPSD (tier 7). They suggest that government funding could be directed at the lower tiers to reduce demand for higher level services and therefore reduce costs to the health care system. They recommend that at this lower level, older adults with no or fewer symptoms of dementia, health promotion interventions can play an important role in preventing or delaying the onset of dementia in the older adult population. Currently there are no specific interventions or approaches that are clinically proven to reduce the incidence of dementia.

Building community participation and awareness

A recent study reported in the J*ournal of Neurology Neurosurgery and Psychiatry* suggests that feeling lonely, as distinct from being/living alone, is linked to an increased risk of developing dementia (Holwerda et al. 2012). The Amsterdam Study of the Elderly (AMSTEL) explored the risk factors for depression, dementia, and higher than expected death rates among older adults. This research has important implications for health and social policy directions, given the number of older Australians who live alone and also are lonely. The BSL acknowledges that combating loneliness and social isolation is a difficult policy area, but we consider that a capabilities approach is needed, where services work with older adults to determine what skills and resources they need to pursue a life of value. We have successfully provided this support, helping people to participate in community-based lifestyle and leisure activities through a person-centred approach, regardless of whether behavioural and psychiatric symptoms of dementia are present. We also provide dementia-specific social events and activities through our Social Inclusion Program which has been operating for more than six years. This program has not been allocated specific funding by government.

To maximise social participation, the BSL recommends a whole of community approach that focuses on the engagement of local community groups to do more to assist older adults and those with dementia to participate in leisure activities.

Recommendations

Governments need to provide long-term funding to peak dementia organisations such as Alzheimer's Australia, or their state branches, to deliver community dementia awareness campaigns, especially among community clubs and groups which already have high proportions of older adult members. Campaigns need to:

- provide examples of programs under which people with dementia can be safely and adequately supported to remain within their club or activity, and describe the positive health and wellbeing benefits
- suggest how community groups can be more supportive of people with dementia participating in their activities with simple strategies as reminder phone calls, providing transport, helping people feel comfortable and welcomed.

To achieve this, it would be advantageous for governments to foster closer ties between local community groups and aged care service providers which can provide the expertise and the support in working with older adults with dementia, by offering community grants that provide the necessary resources.

Dementia Care Pathway model

BSL also recognises the importance of strategies when people are already dealing with dementia and BPSD. We have developed a model of dementia care called 'The Dementia Care Pathway': this assists clients/carers and professionals to negotiate the journey through the dementia experience and involves a Dementia Care Consultant (DCC) and Dementia Care Coordinator (DCCo) who provide expertise, consultancy, advice and support.

The Dementia Care Pathway model represents the progression of dementia care through the three stages, early, middle and late, and suggests an intervention or service as any new issue or symptom emerges. Supports and services may be accessed within the BSL and in the broader community. It is currently a tool for all BSL staff, particularly Care Managers who are key workers for all people with dementia and BPSD and their carers utilising Home Care Packages, and helps them to recognise changes and the need for current and future planning.

The model allows entry at any stage of dementia, with specific information and responses tailored for each stage. It represents a person-centred approach to dementia care, realising that individual clients and carers will have diverse needs.

As dementia is a degenerative neurological disease, symptoms change: some become worse and some new symptoms appear as the disease progresses. For most people with dementia, BPSD are a symptom of the disease's progression. As people's capacity to communicate verbally deteriorates, communication is often displayed through behaviour.

BPSD usually occur in the middle stages of dementia, so it is here that critical interventions must be put in place as each new symptom appears. Using the BSL model, the BPSD are managed over the months or years over which they occur before they reach the tipping point where the sheer difficulty and distress of caring for someone with dementia and BPSD becomes, in the eyes of the carer, impossible and so care is relinquished.

The BSL considers that BPSD are able to be managed through a variety of strategies other than physical and chemical restraint and by specialist staff and services such as those offered through BSL's day and respite services, Short Break Stay community residential respite, Caring for Carers program and Home Care Packages. As a result the BPSD are managed for a time, the condition plateaus and the carer is able to continue to provide care. The behavioural and psychiatric symptoms may change over time, and again strategies are put in place. Life for the person with dementia and BPSD and their carer is able to continue in the community, surrounded by family, friends and support services.

When residential care is necessary, BSL’s facilities also ensure that BPSD is managed through observation and understanding the person’s life history which provide insight into the appropriate options available. Use is also made of Talking Mats, a communication tool which assists residents with mild to moderate stages of dementia, to communicate their emotions, needs, lifestyle interests, personal care, likes and dislikes. Talking Mats, developed by the AAC Research Unit, University of Stirling, are an interactive resource that uses three sets of picture symbols—topics, options and visual scale—and a textured mat on which to display them. Taking the time to use the picture symbols and visual scale assists in building relationships between residents and staff, assists with documentation (e.g. care plans, progress notes) and most importantly ensures staff are able to identify areas that require more attention (e.g. pain, personal care and lifestyle choices). Hence the correct services and options are being provided to the person in care to enhance their quality of life. Overall, the staff feel they gain a better understanding of each resident’s needs and feelings, and residents feel more confident in communicating their needs and feelings. This results in better care and interaction.

BSL’s model is underpinned with expert professional staff. It is critical to ensure adequately skilled and funded health professionals are available to increase the capacity of community organisations working with and supporting people with dementia with BPSD and their carers. As the percentage of the population with dementia and BPSD increases, the availability of these experts, and not just nursing professionals, at the critical touch points a person with dementia and BPSD and their carer encounter will be the difference between that family remaining together in the community and the family unit being broken up due to one member going into care.

BSL’s dementia model has resulted in specific programs such as the Caring for Carers program, which provides one-to-one carer support for one hour per week for eight weeks and follow-up support for 24 weeks. Both stages are delivered in the carers’ homes by a project worker trained in diversional therapy and experienced in dementia care. Carers are trained in behavioural therapy techniques with the aim of reducing the prevalence and effect of difficult dementia-related behaviour. Other elements of training include diversional therapy strategies, practical advice, forward planning, pleasurable events and information relating to dementia and the available care services. These elements, delivered according to carer need, serve to support the carer in their role. Carers are also encouraged to take up additional support services, such as respite.

An evaluation of the Caring for Carers program (Carr, Kimberley & Mercieca 2013) indicates that it 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 beneficial throughout the three 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.

Recommendations

- Investigate the benefits of preventative health promotion programs for the early stages of dementia to reduce the possible development of BPSD
- Implement models of care along the lines of the BSL model of Dementia Care, which highlights the benefits of strategic interventions along the dementia pathway.
- Ensure dementia is core business for Medicare Locals across Australia, within their mandate to provide essential primary health and service coordination.

- Ensure there is a dementia expert, not medical, on the Board of every Medicare Local nationally.
- Give Medicare Locals the responsibility for improving GP knowledge of the options and experts available in the community for managing dementia and BPSD, beyond prescribing medication.
- Provide funding for expert health professionals such as Dementia Care Consultants in community care settings to ensure that people with dementia and BPSD receive the right advice and service at the right time.
- Provide funding for innovative models such as BSL’s Caring for Carers Program
- Provide education and training for community and residential aged care staff in understanding and managing the causes of the individual’s behavioural and psychiatric symptoms of dementia.

(c) The scope for improving the provision of care and management of Australians living with dementia and BPSD such as:

(i) Access to appropriate respite care, and

(ii) Reduction in the use of both physical and chemical restraint

Access to appropriate respite care

Day care / respite (community based)

As more and more people with dementia continue to live in the community, day care (respite) services will be in high demand. However the challenge for the day care / respite sector is how to continue to support people with BPSD within a social model of care.

Currently day care / respite services are delivered by agencies in the form of planned activity groups funded by the Department of Health through the Home and Community Care (HACC) and Carer Support Program and /or by the Department of Health and Ageing through the National Respite for Carers Program (NRCP). The NRCP program does fund some agencies to deliver respite care to people with high care needs; however there has been no growth in funds since 2007 to meet the increased demand or provide alternative models of respite for people with more extreme BPSD.

For many people with dementia and their carers, a service such as day care is vital to sustain living in the community. Although there is recognition of the significant benefit of day care / respite for the person with dementia and their carer there is also evidence that the current structure is unable to meet the needs of individuals who are showing more than one behavioural symptom of dementia (Mavall & Malmberg 2007). This exclusion not only has a detrimental impact on the person with dementia but also impacts on their carer and places both at risk of increased isolation.

The BSL has received referrals requesting day care for a person with dementia who could no longer access mainstream day care / respite as a result of their BPSD. The referring agency has indicated that the BSL’s Banksia Services program is recognised as a specialist dementia service that is able to provide the type of support required. The lack of other appropriate service organisations able to provide assistance for people with multiple BPSD supports the literature which indicates that people with BPSD end day care earlier than those who have fewer problems.

There is also a need to review the current residential respite model which is delivered by some residential facilities. A needs analysis report completed by the BSL in 2010 identified a shortage of high-level aged care residential facilities for people with BPSD in the southern part of the Southern Metropolitan Region of Melbourne. Those services which did exist were unable to be flexible in the respite offered due to funding requirements, and were rarely equipped to support people with BPSD.

Carers of people with dementia had been dissatisfied with existing services because facilities could not meet their family members' needs and typically required a minimum two-week stay. Carers were concerned about the length of separation, especially if the staff had little expertise in dementia care. Carers' experience of this type of respite has highlighted problems such as the following:

- Without careful management, a change in the environment can often trigger a change in behaviour or an exacerbation of existing behaviours in the person with dementia.
- Carers often find it difficult to let go and trust that everything will be all right for their family member. Carers Victoria found that most carers using respite services for the first time experience increased anxiety about the person they care for.
- Carers often have feelings of guilt about using respite services and struggle to relinquish the care.

Recently carers who belonged to the BSL's Banksia Carers Support Group spoke about their recent experience with residential respite. The feedback was negative and clearly identified the providers' lack of experience in delivering respite services to people with BPSD within a residential facility.

Resourcing appropriate respite care for people with BPSD

As reported by Brodaty, Draper and Low (2003), BPSD are associated with lowered functional abilities, poorer prognosis, an increased burden on carers and day care / respite staff, higher costs of care and earlier admission into residential care. Therefore the adequate resourcing of day care / respite is essential to the support of people with BPSD. Currently funding through the HACC and NRCP programs can meet the needs of people who exhibit one or two BPSD if the organisation specialises in dementia care and provides a social and physical environment which is conducive to the person's wellbeing.

Although some people come into the Banksia Services programs when they are unable to access other community respite programs owing to their BPSD, once their condition becomes more extreme (with more than two BPSD) their needs exceed the resources of the Centre. Often the person will require more intensive support with activities of daily living and activities of engagement as the combination of behaviours creates more agitation and confusion requiring additional staff time in order to determine the unmet need. This intensive support cannot be met within the current 1:5 staff to client ratio model funded under the HACC program (PAG High). It has been the BSL's experience that when the carer is notified that day care / respite can no longer be provided, many carers will then decide to place the person into residential care. A carer once commented:

> If you can no longer care for my wife no one else will be able to care for her—not even me—maybe it is time for residential care.

BSL carers have reported that using regular short break stays enabled them to continue caring for a longer period, delaying entry into residential care. One carer stated that she ‘felt more comfortable leaving her mother at Banksia than in a nursing home for respite’. Regular short break stays enabled this carer to continue working while caring for her mother (who had dementia with BPSD) until her death a few weeks ago. If the family member had been placed in residential care, the funding received for her care would have been some $60,000 per annum. The BSL has many carers who do not receive any services other than respite, making it a cost-effective option.

Community-based residential respite

The BSL is committed to a shared vision and understanding of the management of BPSD in order to support people as their dementia progresses. In July 2010 the organisation, in partnership with Commonwealth Respite & CareLink Centre Southern Region (CRCCSR) developed the Short Break Stay program to provide short-term residential care for people with high care needs as a result of BPSD. These breaks were offered monthly for 15 months. Unfortunately, this program is currently not being delivered as there is no recurrent funding.

The physical and social environment plays an integral role in care at the Banksia Community Respite Centre. The centre has been designed to offer a dignified care environment and provides people with advanced dementia with a three-day stay in a homelike environment with stand-alone devices that support independence and safety. There are six bedrooms, a fully equipped kitchen, and dining and lounge area in an open-plan arrangement.

The Short Break Stay offers a safe environment, with the security measures discreetly hidden through the way furnishings are arranged and where doors are placed. One carer referred to the centre as the ‘Banksia Hotel’. Appropriate staffing is fundamental to the Short Break Stay program: all staff have experience not only in managing the symptoms of dementia but also in managing behavioural changes. Staff also understand how to maximise the use of the environment in order to manage behaviours often associated with confusion, fear and agitation.

The staffing ratio for the Short Break Stay is unique among services and enables a person centred care framework. Two staff, a personal care worker and an enrolled nurse are on duty at all times for a maximum of six attendees. Apart from formal qualifications staff members are chosen for their particular qualities which include confidence, the ability to relate to others and show empathy, active listening skills and the ability to work with people who have limited communication skills.

Ensuring a person with dementia is safe and secure is paramount. Therefore it is important to identify an unmet need in order to manage the behaviours displayed. The approach is structured to enable us to plan and examine the quality of life of people with dementia when they are receiving the service. The diversional therapist develops a stimulating activity program as well as a creative behavioural support plan to suit individual needs. These tools assist the staff member to use a person centred care framework.

Day care / respite

In order to continue to provide respite to carers of people with dementia and BPSD an integrated model is required. The BSL has been able to continue to support people with more extreme BPSD using a fee-for-service model. The additional funding enables an extra staff member to assist with the more intensive support required. However this model has limitations as it requires three people to access this service to make it a viable option. Integrating the extra care into the generic day care /

respite program has been successful as all staff members work as a team and the person with more extreme BPSD can feel part of the group; and when individual attention is required the additional staff support is available.

Recommendations

Since behavioural symptoms appear in 61% to 88% of people with dementia living in the community, a better approach in addressing more extreme BPSD within the day care sector is required. This includes community-based respite.

- Enable dementia specialised ‘day centres’ to continue to support people with more extreme BSPD by providing additional funding for a 1:3 staff to client ratio where required. The model would be integrated into current specialised day centres.
- Provide an alternative residential respite model of care based on the BSL Short Break Stay.

Reduction in the use of both physical and chemical restraints

While there are many interventions and supports, it is important to make a special mention of chemical restraint. Medical professionals in Australia, the United Kingdom and the United States are unnecessarily treating people with dementia using antipsychotic drugs instead of effectively managing the behavioural and psychiatric symptoms, according to Britain’s top dementia policy expert. Professor Sube Banerjee, who wrote the *The use of antipsychotic medication for people with dementia: time for action* commissioned by the UK Government, and recently visited Australia, has warned that the over-use of antipsychotic medication in people with dementia is not just a medical concern but a human rights issue (Noone 2012).

Professor Banerjee asserted that medical professionals are chemically restraining people with dementia using antipsychotics, instead of managing their behavioural and psychiatric issues using non-chemical means. He stated that although there is a place for antipsychotics in the proper treatment of dementia, it should be the last resort, not the first. The BSL’s experience is that people with BPSD can be managed by paying attention and gaining a better understanding of the underlying causes of the behaviours so that more appropriate strategies can be applied.

In addition, as BSL noted earlier, if a GP is not aware of the suite of options available, then the only option offered will be medication. Thus education of GPs is imperative to enable appropriate assistance for people with dementia and BPSD and their carers.

If people with dementia and BPSD can be supported longer at home with the best strategies—both community and medical—during the critical middle period when BPSD is accelerating, carers will be able to extend their caring time by building the necessary resilience to move beyond the middle stage to the palliative or end stage of the disease, when BPSD symptoms greatly reduce.

Recommendation

- Ensure that the human rights of people with dementia and BPSD are upheld and that physical and chemical restraint is seen as the last course of action in managing their behaviour. This could be incorporated in the Department of Health and Ageing Charter of Rights for Residents and Community Care Participants and Guidelines for Service Provision which would then be monitored throughout the aged care service industry.

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