



BRIGHTwater

Senate Community Affairs Committee Inquiry into care and management of behavioural and psychological symptoms of dementia (BPSD) in Australia

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Introduction

Brightwater Care Group is one of Western Australia's best known and largest providers of quality residential, rehabilitation and community care for older people and people with acquired disability. We provide residential accommodation for older people in 23 facilities located across the Perth metropolitan area, including several specialised dementia designed facilities. Brightwater also provides accommodation and support for people living with Huntington's disease, and a range of rehabilitation and residential accommodation for younger people with acquired disability. Brightwater has an extensive At Home Service providing HACC and Community Aged Care and Extended Aged Care at Home (including Dementia) packages plus Transition Care Services for older people after their discharge from hospital.

Brightwater is a key partner in a unique and national initiative, the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in the Elderly. This enables our engagement and collaboration in applied research, translation of evidence into practice and change management that will impact on the wellbeing needs the elderly experiencing cognitive changes, including dementia and BPSD.

This submission is based on our experience providing care and support to people with dementia in metropolitan Perth. Throughout this submission the term BPSD is defined as behavioural and psychological (**not** psychiatric) symptoms of dementia, as agreed upon at the International Psychogeriatric Association Conference in 1996.

Brightwater's purpose to 'enable wellbeing', our values and fundamental philosophy of personhood provide a framework that underpins our approach to providing care and support in the community and residential care to people with dementia, including those who experience BPSD. Our approach recognises that like the signs and symptoms of dementia, the experience of BPSD will vary from person to person. We aim to support the person with dementia and their family along their dementia journey, providing continuing care and support as their needs change and they transition between services. Brightwater's models of care are responsive to emerging research and best practice and aim to address the underlying needs and experience of the individual rather than their 'challenging behaviours'. We acknowledge that BPSD has an impact, not just on the person with dementia, but their family and staff providing care and that it is treatable or reversible with appropriate strategies. .

Brightwater believes it is essential to resource the mechanisms of change required to transform the current biomedical model of dementia care and management of BPSD to one that enables service delivery models in all settings to effectively deliver

person-centred care based on understanding the individual and their experience of dementia and BPSD. To this end, a radical re-orientation is required, away from the biomedical model towards a partnership model that involves the person with dementia, including those experiencing BPSD, their families and care and support staff.

Our submission addresses the issues specifically concerning the care and management of BPSD under each of the Senate Inquiry's Terms of Reference.

A. What is the scope and adequacy of the different models of care and management of behavioural and psychological symptoms of dementia (BPSD) in Australia?

A 'model of care' is an overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, evidence based practice and defined standards. It consists of defined core elements and principles and has a framework that provides the structure for the implementation and subsequent evaluation of care (Davidson et. al., 2006. *Beyond the rhetoric: what do we mean by a 'model of care', Australian Journal of Advanced Nursing*). This definition serves as a reference when commenting on the scope and adequacy of services for the care and management of BPSD in Australia.

In the Community

People with dementia living in the community currently access care and support services from Home and Community Care (HACC) and Community Aged Care and Extended Age Care at Home (including Dementia). Access to community services, as part of the Living Longer Living Better Aged Care reforms, is soon to be through a single Gateway with the core functions of information, assessment, matching and referral. In WA, the experiences of people with dementia and their families since the introduction of the WA HACC Assessment framework on 31 January 2011, serve to highlight the particular challenges of this model for people with dementia and their families, particularly those impacted by BPSD.

There is limited capacity in the current WA HACC Assessment framework or proposed Gateway to recognise that it is the 'Carer', the person who has assumed responsibility for the wellbeing of the person with dementia experiencing BPSD, who makes the initial contact seeking assistance for the 'Client'. The need for assistance and support is frequently not recognised by the 'Client', the person with dementia, particularly if they are experiencing BPSD. Therefore, given the complex nature of dementing illnesses, when it comes to an assessed need for community services, consideration should be given to the needs of two 'Clients', the obvious one being the person with dementia and the other their spouse, family member or friend, who is seeking to assist them live independently in the community.

Neither the current Assessment framework nor the proposed Gateway supports early intervention for people with dementia and their families which can reduce or minimise the impact of BPSD. If memory or behavioural concerns are not triggers for referral for a more comprehensive assessment, then the opportunity to provide early intervention and potentially reduce or minimise issues associated with BPSD is lost. In addition, there has been an increasing reluctance on the part of General Practitioners and Aged Care Assessment Teams (ACAT's) in WA to confirm a diagnosis of dementia in writing. This too has an impact on opportunities for referral and early intervention and may have broader repercussions once the eligibility criteria for the new dementia supplement for community care services are released.

Community care assessment and service delivery models remain service driven, despite the introduction of consumer directed care. Allowing consumers to make choices about the types of care they access is a positive initiative, but only if the range of services offered are responsive to their needs. Carers, whether they are co-resident or not, of people experiencing BPSD require specialist services in addition to and in combination with current services provided to support a person with dementia live independently in the community. Currently there are no service types in community care to provide carers of people experiencing BPSD with individualised education and support to identify strategies and interventions that address the specific needs of the person with dementia.

Meeting the needs of people experiencing BPSD within current community care service types is also a challenge. Often a service requires a level of flexibility and creativity to ensure that the care and support provided is truly person-centred and acceptable to the person experiencing BPSD, who may have a different insight into their needs than their family or assessment agencies. It is essential that interventions supporting people experiencing BPSD are consistent, both in approach and in personnel. Acceptance of community care and support is dependent upon a relationship built on trust, usually between the person experiencing BPSD and one or two support staff. Therefore, it is critical for the effectiveness and success of services provided to people experiencing BPSD that community care services consistently roster the same staff to provide their community care and support services, and those same staff have the necessary attitudes and skills to develop a relationship with the person that enables them to respond appropriately to meet their individual care and support needs.

In order to meet the needs of people experiencing BPSD and their families living in the community, Brightwater At Home Services have implemented a broad range of initiatives including:

- Building the capacity of all At Home Services staff to meet the needs of people with dementia, including people experiencing BPSD living in the community, through regular information sharing, skills development and training;
- Creating a specialist At Home Services team of support staff who have demonstrated a mindset and attitude for supporting people experiencing

Behavioural And Psychological Symptoms Of Dementia (BPSD) In Australia

BPSD, utilising a range of person-centred care approaches (eg. *Spark of Life*);

- Providing ongoing practical support, mentoring and skills development to staff and families providing care to people experiencing BPSD, from a small team of experienced staff skilled in implementing person centred care;
- Employing regional Allied Health teams, comprising Occupational Therapists, Physiotherapist, Speech Therapists and Social Workers, who play a significant role in community service care plan development, review and case conferencing; provide education and support for families and staff; develop and provide training in the use and application of individualised communication strategies, exercise programs and meaningful activity resources for staff and families, particularly for people experiencing BPSD.
- Consistently raising the awareness of families of the benefits of planned respite for people experiencing BPSD, to prevent 'carer burnout', reduce premature admission into residential care and improve its acceptance when and if required.
- Regular internal transition meetings between senior staff from Brightwater At Home Services and Residential Aged Care Services to identify and plan for the changing needs of people with dementia, including those experiencing BPSD.

Suggested improvements in community care include:

- Changes to current and proposed Gateway assessment documentation and processes or creation of an additional dementia specific needs assessment tool that takes into account the impact of cognitive impairment and BPSD on the person with dementia's function and capacity. It is critical that assessments are psychosocial, not biomedical.
- Making 'providing care or support for a person with dementia' a trigger for referral for comprehensive dementia specific needs based assessment that recognises the carer of a person experiencing BPSD as a client in their own right.
- Creating and resourcing community care services for carers of people experiencing BPSD that includes support for the carer to improve their understanding of their experience and reactions to caring and carer stress. This includes communication strategies and problem-solving to improve the social and physical environment and enable the carer to better support the person experiencing BPSD and improve their own wellbeing.
- Creating and resourcing services designed specifically to address the unique needs of younger people experiencing BPSD, and their families.
- Creating and resourcing community care services for people experiencing BPSD that includes a team of skilled staff trained in person centred approaches (eg. *Spark of Life*) who are consistently rostered to provide services that are responsive to the changing needs of people experiencing BPSD, including providing opportunities for engagement and interaction in meaningful activities that are based upon their strengths and abilities.

- Providing additional resources for community based dementia specialist services like the McCusker Nurse in WA, which offers tailored one-on-one support, information and guidance to people living with dementia, including those experiencing BPSD and their carer/s and family members.

In Residential Care

People with dementia, including those experiencing BPSD will continue to require access to residential care, despite Aged Care reforms to increase support to enable people to receive care at home for as long as possible. In residential care it is widely recognised that a human services model of person-centred care does support and promote the wellbeing of people with dementia, including those experiencing BPSD. However efforts to bring about cultural change in residential care, to implement a person-centred approach, are hampered because the current structure and system of residential care in Australia continues to operate within a biomedical model of dementia, thereby sustaining a disease and deficit based approach to dementia care.

In addition, the current system of funding residential care does not support nor promote person-centred practices, particularly in regards to people experiencing BPSD. The Aged Care Funding Instrument (ACFI) is intended to assess the core care needs of a person with dementia as a basis for allocating the residential care supplement for behaviour. The focus of this assessment is on behaviour as a problem to be 'managed', implying that the person exhibiting the symptoms is the problem, rather than enabling the behaviour to be viewed as a symptom of unmet need and encouraging critical analysis to determine the underlying reasons and causes.

The so-called 'behaviours of concern' referred to in the ACFI documentation as verbal or physical aggression and wandering are not symptoms of dementia, which are progressive and irreversible, nor are they directly caused by the dementing illness. They are more often caused by the person reacting to unmet need/s and physical, environmental, social and emotional stressors or events that they cannot manage without our support and without a change in our perspective and our behaviour.

Judging and labelling a person's behaviour does not relate to what the person is experiencing or feeling. However it does cause a general belief among many staff in residential care that the symptoms of BPSD are inevitable rather potentially reversible with a person-centred approach to care that acknowledges the psychological, social, cultural and spiritual differences between individuals. It also prevents a person's actions being viewed as indicative of their strengths and abilities. For example, wandering and intrusiveness are currently classified as behaviours that attract funding to assist their 'management'. From a truly person-centred perspective the person's action of searching would be viewed as evidence of their ability to interact with and get around their environment, and of a range of skills they are seeking to utilise.

The Aged Care reforms provide additional funds to residential care for ongoing support to people experiencing severe BPSD. Despite this, without major cultural changes to current models of care there will always be a requirement for specialist care facilities for those people experiencing very severe BPSD who require short term placement to address and treat problematic symptoms, or long term placement because they are a potential danger to other residents and staff. Currently there is an 18 month waitlist for access to the only two high dependency units providing this type of specialist care in WA.

In order to meet the needs of people experiencing BPSD living in residential care, Brightwater Residential Aged Care Services have implemented a broad range of initiatives including:

- Brightwater's residential aged care accommodation has been designed and built according to principles of good dementia design to enable people's freedom within a safe and secure environment that facilitates way-finding, meaningful engagement and interaction in the indoor and outdoor environments. These environments are essential in supporting and minimising the impact on a person's experience of BPSD;
- Implementing a range of person-centred approaches that focus on understanding the individual needs and experiences of the person with dementia and creating a person-centred environment in diverse residential care settings that range from:
 - Brightwater The Village which comprises 65 private rooms in six connected houses that caters for people living with dementia who are independently mobile and need high care support.
 - Brightwater Edgewater which comprises 33 private rooms in four co-located houses providing 'ageing in place' for older people including those requiring dementia care.
- Piloting well-being mapping for people experiencing BPSD, a process that is now being progressively implemented across Residential Aged Care Services. Wellbeing mapping facilitates a person-centred assessment and problem solving approach to care planning based upon concept mapping. (Aberdeen, Leggat & Barraclough, 2010. Concept mapping a process to promote staff learning and problem solving in residential dementia care. *Dementia* 9 (1), 129-151). Wellbeing mapping does not replace normal assessment processes, but facilitates a group of staff including direct care staff plus family members to undertake a person-centred analysis that improves understanding of the needs of the person experiencing BPSD, identifies strategies and interventions for care planning, improves the skills and knowledge of staff and their capacity to deliver individualised care, and provides a mechanism for monitoring and evaluating outcomes;
- Seeking to create a partnership approach with DBMAS and OAMHS by strengthening processes for communication and collaboration to improve outcomes for people experiencing BPSD in residential care;

Behavioural And Psychological Symptoms Of Dementia (BPSD) In Australia

- Reviewing and implementing changes to current dementia and BPSD training programs provided to staff, volunteers and students, including opportunities to work directly with direct care staff to incorporate wellbeing mapping and Spark of Life principles into their approach to supporting people experiencing BPSD;
- Employing Allied Health staff comprising Occupational Therapists, Physiotherapist, Speech Therapists and Social Workers in each residential facility, who play a significant role in care plan development and review, implementation and review of therapy programs; providing support to families; and developing and providing training to staff;
- Developing a Living Environments team of skilled staff to provide an evidence based approach to the development of Brightwater standards for the design and ongoing maintenance of the ambience, décor, furniture and fittings of Brightwater residential accommodation. This will ensure the refurbished physical environments are enabling and support the needs of people, including those with BPSD;
- Developing and delivering an Enabling Environments training package that increases staff knowledge, understanding and skills to create and maintain a person-centred environment. The three tiered package addresses the needs of the professional staff, the support staff and the people living in the residential aged care facilities;
- Providing inter-professional fieldwork placement opportunities for students from a range of health sciences disciplines including medicine, to develop practical skills, knowledge and understanding of the individual needs of a person living with dementia, particularly those experiencing BPSD and the influence of a person-centred approach to improving care outcomes;

Suggested improvements in residential care include:

- Resourcing the mechanisms of change required to underpin interventions in service provision that address BPSD, such as the person-centred assessment and problem solving approach based on concept mapping; regular onsite staff training and mentoring in approaches that support person-centred care eg. *Spark of Life*;
- Improving existing residential environments so they enable the wellbeing of people with dementia, support person-centred care and minimise the impact of environment on BPSD by considering aspects such as lighting, signage, furniture and fittings;
- A comprehensive review of the appropriateness of the core care needs for behaviour currently used in the ACFI funding tool to assess the person with dementia for allocation of the residential care supplement;
- Distinguishing between behavioural and psychological symptoms of dementia that impact on care provision. Psychological symptoms of dementia include delusions and misidentification syndromes such as hoarding, paranoia and suspicion. Symptoms linked to an individual's psychological, social and cultural differences should also be included in any review of the core care needs of a person with dementia;

- Resource to develop and implement quality standards for enabling environments in dementia specific accommodation based on dementia design principles;
- Providing capital and recurrent funding to pilot the creation of small aged care houses for 6–10 people based on The Green House[®] Project model (<http://www.rwjf.org/en/grants/grantees/the-green-house-project.html>) and evaluating the cost/benefits for aged care in Australia;
- Providing capital and recurrent funding for additional special care units to accommodate people experiencing severe BPSD.

In Acute Care

Acute care is a dangerous environment for people with dementia, including those experiencing BPSD. It is frequently the nature of the acute care environment and care provided, that contributes to a person with dementia developing BPSD following admission, including and particularly in Emergency Departments. The Aged Care reforms to improve acute care services for people with dementia are a beginning, however a comprehensive long term strategy is required to build on these reforms and ensure that the specific needs of people experiencing BPSD are recognised and addressed within the biomedical model of care that exists in the acute care environment.

Brightwater aims to provide ongoing care in the community and in residential care to people with dementia, including those experiencing BPSD, and avoid admission to acute care unless there is complex health, physical or psychiatric care needs. The organisation has employed two Nurse Practitioners, under the Commonwealth funded Nurse Practitioner Model of Practice Project. Their screening processes, comprehensive health assessments, preventative health care and chronic disease management practices, in conjunction with visiting GPs, play a significant role in supporting people with dementia, and reducing the incidence of BPSD.

Residential Aged Care Services provide comprehensive information about the person with dementia's individual care needs to acute care services whenever a person with dementia does require admission. This information is not always utilised to improve the acute care experience for the person with dementia and minimise the likelihood of BPSD. Discharge practices, communication and liaison regarding a person with dementia returning to the community and to residential care also could be improved to maintain the person with dementia's wellbeing.

Suggested improvements in acute care include:

- Recognition that acute care does not meet the needs of people experiencing BPSD, and establishment of appropriate sub-acute services in the community including residential care environments;
- Resource and implement quality standards for the care of people with dementia, including those experiencing BPSD;

- Resource and implement quality standards for improved collaboration with specialist services, including DBMAS and OAMHS;
- Resource and implement quality standards for acute care environments, particularly Emergency Departments, based on dementia design principles. Age friendly principles are inadequate to meet the needs of people with dementia and those experiencing BPSD;
- Recurrent funding for hospital liaison services that specialise in the assessment, treatment and joint discharge care planning with community and residential care providers of people with dementia, including those experiencing BPSD.

What is the scope and adequacy of BPSD support and services provided by the Commonwealth, state and territory and non government sector?

The current service delivery system for people experiencing BPSD is fragmented and lacks continuity in its approach and model of care, often resulting in a lack of demonstrated cohesiveness between Commonwealth, State and non government services and a poor interface with primary and acute care and with community and residential care services. Fragmentation does not support or promote collaborative approaches between specialist services set up to provide support and care for people experiencing BPSD in any setting they find themselves. Instead it often results in competitiveness, a lack of cooperation and an unwillingness to share information. The lack of integration of services is also particularly burdensome and delivers poor outcomes for people with dementia experiencing BPSD who require services in all settings to be based on a good knowledge of their individual needs and those of their families.

(i) Commonwealth

The Dementia Behaviour Management Advisory Service (DBMAS) in WA provides a BPSD care and management service to people living in residential aged care or the community who are eligible for Commonwealth funded Community Aged Care services. Their service delivery model supports a person-centred approach to dementia care, however it is unclear how effective an external consultancy service can be in influencing changes in the nature of care practices for people experiencing BPSD unless they can be resourced and recognised as agents of change. The scope of DBMAS will be expanded in the Aged Care reforms to include support for people experiencing BPSD in primary care and hospitals. However, currently people with dementia and families receiving state funded HACC services are not eligible for DBMAS services in WA.

(ii) State and Territory

There are a number of Older Adult Mental Health Services (OAMHS) serving different localities across metropolitan Perth whose approach to BPSD is

based on a biomedical model. The service delivery models of each also seem to vary, as does the quality and standard of their engagement and interface with community and residential care providers seeking support and assistance for people experiencing BPSD in their care.

(iii) Non Government Sector

Alzheimer's Australia WA provides a range of services to people with dementia, and to families of people experiencing BPSD through the National Dementia Support Program. In addition they provide a range of information, resources, education and training for families, and for the acute, community and residential care sectors, which includes BPSD.

B. What are the issues in terms of resourcing of the different models of care?

There is a need to resource the model of care that is deemed effective in supporting the needs of people experiencing BPSD. There is widespread agreement that this model is based on a person-centred approach to dementia, rather than a biomedical approach. Mainstream and specialist BPSD services require resourcing that enables a partnership approach to person-centred care and management of BPSD. This ensures the individual needs and experience of the person with dementia and their family is the focus, rather than 'problem behaviours'.

In residential care, an alternative ACFI that supports a person-centred approach to meeting the individual needs of people with dementia, including those experiencing BPSD is required. The abilities of people with dementia can fluctuate on a daily basis and resourcing the level of support they require should be based upon the individual's experience of dementia to minimise the impact and incidence of BPSD.

The limited number of Medicare rebates available for services provided by Nurse Practitioners in community and residential aged care reduces access to a service that significantly benefits people with dementia, plays a role in preventing the onset of BPSD and contributes to improved care and management of BPSD. Therefore consideration must be given to increasing Medicare rebates for Nurse Practitioners to enable providers to employ them in a sustainable business model.

Mainstream and dementia specific community and residential care services, including day centres, residential care and psycho-geriatric units create social and physical environments that significantly impact on people with dementia and frequently contribute to their experience of BPSD. Existing services require resourcing to improve their environments so that they meet current evidence-based dementia design standards.

C. What is the scope for improving the provision of care and management of behavioural and psychological symptoms of dementia (BPSD) in Australia, such as:

(i) Access to appropriate respite care

Depending upon eligibility, respite services for people experiencing BPSD are provided in the person's home, in community based facilities like a day centre and in residential care facilities. Preparation and planning is critical for successful respite outcomes for people with dementia experiencing BPSD, particularly residential respite, because of the unfamiliarity of the environment.

The decision to access residential respite is generally made by the family carer and can signal the beginning of a transition into residential care. The success of residential respite is often more dependent upon the family's understanding and acceptance of the need for respite and how realistic their expectations are of respite and respite outcomes. A successful residential respite outcome is beneficial to both the person experiencing BPSD and their family as it most often influences the nature and experience for both when the need arises to accept and transition into residential care.

Suggested improvements to ensure access to appropriate respite care includes:

- Ensure that respite is categorised as a 'basic' care need in the assessment framework.
- Review and adequately resource the current residential respite funding model recognising the increasingly complex care needs of people requiring residential respite, particularly people experiencing BPSD;
- Provide capital and recurrent funding for new small scale respite houses located in the community. These should provide more flexible and appropriate accommodation for people experiencing BPSD, many of whom are younger in age, have children at home and a spouse in the workforce;
- Provide funding for additional, alternative and flexible overnight respite options for people with dementia. In the Perth metropolitan area there is only one NRCP funded dementia specific day centre where a person with dementia experiencing BPSD can go for the day, stay overnight and spend the following day as well;
- Resource and implement quality standards for flexible and responsive respite options that demonstrate the benefits of regular planned respite breaks, to reduce carer burden and support the person with dementia, including those experiencing BPSD, to live independently in the community;
- Resource strategies that increase the knowledge and understanding of GPs, all agencies providing information, eligibility assessment and

referral, and community care providers, of the value and importance of respite to families and carers of people experiencing BPSD.

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

The fundamental goal of services in Australia for people experiencing BPSD should be to enable their wellbeing, not to reduce physical and chemical restraints. Use of physical and chemical restraints in the management of BPSD in all settings (community, residential and acute) is further evidence of the continued influence of the biomedical model in dementia care and its view that behavioural and psychological symptoms of dementia are the problem, rather than symptoms of a greater need to change the culture of care. The need is to recognise that the basic human right of a person experiencing BPSD is to receive care and support that is guided by an understanding of them as a person and their individual experience of dementia.

Conclusion

Brightwater Care Group, like many organisations, aims to enable the wellbeing of the community they serve, both in the community and in transition and residential care. People experiencing BPSD require models of care and support that are truly person-centred in their approach. Current policies, regulations, funding and the fragmentation of services, many of which continue to take a biomedical approach to dementia, hinder the quality and effectiveness of services for people experiencing BPSD.

Brightwater Care Group is confident that the Senate Committee will carefully consider this submission and make recommendations to improve outcomes for people experiencing BPSD and their families.