

**FIGHT ALZHEIMER'S  
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**CARE AND MANAGEMENT OF  
AUSTRALIANS LIVING WITH  
DEMENTIA AND BEHAVIOURAL AND  
PSYCHOLOGICAL SYMPTOMS OF  
DEMENTIA**

**Senate Inquiry**

**May 2013**

**ALZHEIMER'S AUSTRALIA**

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## EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the Senate Inquiry into the care and management of individuals with Behavioural and Psychological Symptoms of Dementia (BPSD) as there are serious concerns about access to quality of care for people with BPSD both within mainstream service and in access to specialised services for those with more severe BPSD.

Most people with dementia will experience BPSD at some point in the course of their disease. These symptoms will range in severity, type and frequency and will have different impacts on care needs. BPSD is often transitory, with symptoms at times only lasting for a few weeks or months and rarely lasting for more than two years and in many cases can be prevented or alleviated through management of medical conditions and addressing unmet needs.

It is estimated that at any one time 40% of individuals with dementia in the community may have no BPSD, 50% have mild to moderate BPSD and 10% severe. The care and support required for individuals with milder symptoms of BPSD differ from that required by individuals with more severe symptoms. For the approximately 32,000 individuals in Australia with severe BPSD main stream aged care services may not be able to meet their needs and short-term specialised care which provides interdisciplinary care including support from mental health specialists may be more appropriate.

Both groups struggle to get access to appropriate care. People with mild to moderate BPSD may be turned away from respite services because their needs are considered to be too demanding. Within residential care, they may be inappropriately prescribed antipsychotic medications to control behaviours or are physically restrained without consent of their family carer. Individuals with the most severe behavioural symptoms struggle to get access to the specialised mental health services they need due to barriers between Commonwealth funding of aged care and state funded mental health services. As a result some may spend months in acute care wards because there is no where else that is willing or able to provide care for them. Dementia Behaviour Management Advisory Service (DBMAS) in QLD have reported cases where individuals with severe BPSD have been in acute care for over two years due to a lack of appropriate services.

There is good evidence from both Australia and overseas on the best practice for care for individuals with BPSD including psychosocial and behavioural interventions that prevent and respond to behaviours and appropriate design of aged care facilities. The challenge is ensuring that this practice is adopted in residential and community care. In theory, the accreditation standards should protect individuals from poor care. There are a number of principles outlined by the standards that should ensure access to appropriate care for all residents including:

- "Residents' physical and mental health will be promoted and achieved at the optimum level in partnership between each resident (or his or her representative) and the health care team."
- "Residents retain their personal, civic, legal and consumer rights, and are assisted to achieve active control of their own lives within the residential care service and in the community."

But the reality is that despite the Accreditation process and the Aged Care Complaints Scheme, main stream aged care services are often unable to provide appropriate care and the rights of individuals with BPSD are at times being violated through inappropriate use of psychotropic medications and physical restraint.

There are a number of levers which could be used to promote best practice in mainstream care including linking financial supplements to care practice, improving the response time of the complaint system, use of publically available quality indicators, and promoting education and training. There is a need to identify the individuals who require additional support and care and to develop criteria to identify providers who are able to respond to the needs of individuals with BPSD.

The ***Living Longer. Living Better.*** aged care reforms present some opportunities through dementia supplements and expansion of DBMAS, but it will be important to ensure that this funding is targeted appropriately to promote better care. Development of specialised care for individuals with more severe behaviours requires cooperation between mental health services and the aged care system, as well as appropriate funding arrangements between the states and territories and the Commonwealth.

We are hopeful that this Senate inquiry will make recommendations to ensure that the basic human rights of all people with dementia are respected and that regardless of symptoms they have access to the appropriate care and support to meet their needs.

## Recommendations

1. The use of physical and chemical restraints in residential aged care should be carefully monitored and regulated through:
  - Public reporting of the rate of use of psychotropic medications and physical restraints in residential facilities on the proposed 'My aged care' website.
  - Regulation through the Aged Care Accreditation Agency to ensure appropriate consent procedures are in place for the use of psychotropic medications and physical restraint.
  - A streamlined process through the Aged Care Complaints Scheme for consumers who report the inappropriate use of medications in residential aged care such that a response is required by the Agency within 3 working days of a complaint being lodged.
2. As with the provisions for community care services, individuals with dementia should be eligible for a 10% dementia respite supplement. This additional funding should be used by providers to ensure appropriate care for individuals with BPSD.
3. Double the current financial resourcing for DBMAS over the next three years to ensure that the service can adequately support family carers, residential, primary and acute care.
4. Ensure that all health workers in the aged care sector have appropriate training in BPSD and non-pharmacological interventions. This should include training on psychosocial approaches to prevent and respond to BPSD in medical student, nursing and allied health academic programs and in all Aged Care Certificate 3 and 4 programs.
5. The dementia behaviour supplement in residential care should only be provided to aged care facilities that can document that they are able to provide high quality care for individuals with severe BPSD. This should include:
  - Identifying a person within the facility as the behaviour program coordinator. This person would be responsible for identifying staff training needs, ensuring access to appropriate materials and resources, coordinating access to specialist clinicians with expertise in behaviours and ensuring standards are met.
  - A commitment to using no physical restraint except in cases of immediate danger for self or others and document action taken and how soon the restraint has been removed.
  - Documentation of a comprehensive assessment to identify any untreated medical cause of behaviour and to identify any unmet needs and action taken to address those needs.

- An environmental self-audit using a validated tool and evidence to show reasonable steps have been taken to address issues identified through the audit.
  - A regular review of the program (including use of restraint and medications, care outcomes, issues around seclusion).
6. Federal and State Governments should formally work together as part of their commitment to dementia as a national health priority to development and implement specialised community neurobehavioural units which provide specialised mental health services for individuals with the most severe BPSD through matching aged care and mental health funding and services.
  7. Introduction of systems, to reduce unnecessary hospitalisations of people with dementia and to ensure that if hospitalised, individuals with BPSD have access to quality care in an appropriate environment and staff who have training in non-pharmacological approaches to care.

## 1. BACKGROUND

There are over 320,000 people with dementia living in Australia and by 2050 it is expected that this will increase to 900,000.<sup>1</sup> Most people with dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some stage during the course of their illness.<sup>2</sup> BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours.<sup>3</sup> These symptoms complicate care for the individual and require sophisticated care responses.

According to Australian experts<sup>4</sup>, at any one time 40% of individuals with dementia in the community may have no BPSD, 30% are estimated to have mild BPSD and 20% moderate BPSD. The care and support required for individuals with milder symptoms of BPSD differ from that required by individuals with more severe symptoms. 10% of individuals with dementia have severe to extreme BPSD, which equates to approximately 32,000 individuals in Australia.<sup>5</sup> Both the severity and the frequency of behaviours have an impact on care requirements. It may be difficult to provide appropriate care in mainstream services for individuals with the most severe and frequent behaviours due to their high care needs and concerns about potential disruption to other residents.<sup>6</sup>

The causes of BPSD are not always clear but changes in behaviour may be triggered by biological, psychological, social or environmental factors. In many cases these symptoms are an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear).<sup>7</sup> For example, a person with dementia who previously seemed to enjoy mealtimes may suddenly become distressed and scream during meals. This new response may be due to changes in the brain caused by the dementia or could be due to an overstimulating environment or undiagnosed pain that makes sitting on the chair uncomfortable. Screaming may be the only way the individual is able to communicate discomfort. Understanding what has caused the change in behaviour can help prevent or modify the behaviour.

Consumers and aged care professionals report that there is significant difficulty in accessing appropriate care and support for people with BPSD. For example, individuals with BPSD are sometimes turned away from respite services because their care needs are too high. In residential care, some individuals are physically or chemically restrained without the consent of the person or their family carer. A NSW study conducted in three residential care facilities found that for 87% of residents who received antipsychotics appropriate consent procedures were not followed and care was in violation of guardianship regulations.<sup>8</sup> Individuals with the most severe behaviours may spend months in acute care wards because no other services are willing or able to care for them.

The challenges faced by consumers are perhaps best described in their own words. Below is a selection of quotes from consultations completed by Alzheimer's Australia last year.

## Quotes from Alzheimer's Australia's Aged Care Reform Consultations

"People with BPSD who are entering care services are not provided with appropriate care. Challenging behaviours associated with progressive dementia are especially seen as too difficult to cope with in the aged care setting or even in dementia-specific settings."

"My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other people's rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser. He was treated like a dog."

"My husband was turned into a zombie within a couple of weeks. He wandered into a lady's room and then was put on antipsychotic medications. They increased the dose against my wishes. He has been put on four antipsychotics that should not have been used together. He started falling."

"I care for my mother, who has younger onset dementia. Respite took her for one day, and now they refuse to take her; too much hard work...all she did was wander."

"There is willingness to sedate people with Alzheimer's. The nursing home wanted her to be manageable, and therefore sedated her."

"The care manager of the facility we visited said we will take him on a trial run but if he is aggressive we can't keep him. The care manager made it clear she didn't want him because he was much fitter and younger than other residents. She called after 2 days and said he can't stay. I was given no advice on where to go."



## **2. CARE AND MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD) IN COMMUNITY AND RESIDENTIAL CARE**

### ***2.1 Use of Chemical and Physical Restraint***

Chemical and physical restraints are often used in residential aged care facilities to manage BPSD, especially for individuals who are younger as they are more active and can be physically strong. Restraints refer to any method that restricts the movement and/or behaviour of an individual.

Physical restraint can include any device or object that makes it difficult for an individual to leave a room, bed, chair or to physically move their limbs. Examples include posey restraints and bed rails, which a person can not remove themselves.<sup>9</sup> A systemic review conducted in Adelaide estimated that the proportion of residents physically restrained ranged from 12% to a maximum of 47% (a mean of 27%). The range in duration was from 1 day to 350 days (during a one-year follow-up period) and 32% of residents were restrained for at least 20 days each month.<sup>10</sup> When physical restraints are used in non emergency situations, against the resident's will or without appropriate consent, physical restraint is a breach of human rights.<sup>11</sup> Physical restraint is often to protect the resident from harm<sup>12</sup>, however, there is very little evidence that physical restraint protects the resident against injuries.<sup>13</sup> Instead restraint has been associated with psychological distress, physical injury and in some instances, death.<sup>14</sup>

The use of physical restraints has decreased over time but to some extent may have been replaced by antipsychotic medications as a form of restraint<sup>15</sup>. Chemical restraints refer to the use of antipsychotic or other psychotropic medications to control behaviours. These medications are recommended as a last resort after other strategies have been tried. It is important to note that short term use of psychotropic medications can have clinical benefits to the individual with dementia, particularly those experiencing severe BPSD, provided the medication is given after appropriate diagnosis and subject to review. However long-term use is generally inappropriate and often once the medications have been initiated, an individual with BPSD is likely to be administered antipsychotic medications for long periods of time, and sometimes indefinitely. There has been hesitation among some clinicians about withdrawing antipsychotics for fear of recurrence and worsening of the original symptoms. However, a recent Cochrane Review reported that the majority of people with BPSD can be safely withdrawn from chronic antipsychotic medication without detrimental effects on their behaviour or other adverse side effects.<sup>16</sup>

It is estimated that up to 70,000 people with dementia in Australia are on antipsychotic medications<sup>17,18</sup> and that only approximately 10-14, 000 of these people (~20%) derive a clinical benefit.<sup>19</sup> Antipsychotic medications are associated with serious side effects including increased risk of mortality, stroke, seizures, falls and hospitalisation, exacerbation of existing cognitive impairment and confusion.<sup>20,21</sup> For example, up to 50% of patients with Lewy Body Dementia administered antipsychotic medication has increased sensitivity to the drugs leading to serious side effects.<sup>22</sup> Case study 1 is an example of how long term use of antipsychotics had a negative impact on the quality of life of a person with dementia.

**Case Study 1:** A 79 year old man who had previously no history of BPSD or falls at home was placed in permanent residential aged care home. When he arrived he had difficulty navigating his way around the facility due to lack of access to outside areas, signage and cues. He became confused and disorientated, and also distressed because he could not locate his wife. The facility managed his intrusive wandering and distress through the regular administration of antipsychotics. Subsequently, the man had serious falls and was hospitalised. When he returned to the residential facility his lifestyle was transformed from mobile and alert to passive, sedate and immobile. His family was reluctant to request modifications or reductions in the medications as they did not want to risk being refused care at the residential facility and having to find a place in another facility.

*-Provided by QLD DBMAS*

As part of the Living Longer Living Better aged care reforms, the Government has committed to developing publically available quality indicators for residential aged care facilities which will be available on the My aged care website. The use of psychotropic medications and physical restraints should be included in these indicators to create greater transparency about care practices within residential aged care.

The use of antipsychotic medications can also have implications for the legal rights of individuals. Most jurisdictions require that the prescription of antipsychotics is approved by the person receiving the treatment, or if they lack capacity, a proxy decision maker. However, evidence suggests that this requirement is rarely met. A study conducted in NSW residential aged care facilities found that only 6.5% of cases had appropriate consent procedures that were followed before the administration of antipsychotic medications and a further 6.5% had attempted and partially completed substitute consent requirements.<sup>23</sup> Therefore, in this sample of 77 residents, 87% were given potentially lethal antipsychotics in violation of guardianship regulations. Carers may feel pressured into providing consent due to fear of the consequences if they do not, such as removal of the resident to another facility, as mentioned in Case Study 1.

Consumers should have access to a timely responsive complaints process if they are concerned about the use of psychotropic medication or physical restraint in residential aged care. The current process through the Aged Care Complaints Scheme can be lengthy and result in delays in responding to these issues which have immediate impacts on quality of life.

The Aged Care Accreditation Agency should be tasked with ensuring that appropriate consent procedures are in place for the use of antipsychotic medications. They should also be responsible for monitoring the rate of antipsychotic use in aged care facilities. They should set a specific benchmark (eg. 10%) and when rates of antipsychotic use exceed this rate, the facility should be required to provide documentation explaining their strategies to effectively manage BPSD and reduce the use of chemical and physical restraint within their facilities.

## Recommendation 1

**The use of physical and chemical restraint in residential aged care should be carefully monitored and regulated through:**

- **Public reporting of the rate of use of psychotropic medications and physical restraints in residential facilities on the proposed 'My aged care' website.**
- **Regulation through the Aged Care Accreditation Agency to ensure appropriate consent procedures are in place for the use of psychotropic medications and physical restraint.**
- **A streamlined process through the Aged Care Complaints Scheme for consumers who report the inappropriate use of medications in residential aged care such that a response is required by the Agency within 3 working days of a complaint being lodged.**

## *2.2 Respite*

Many individuals with mild to moderate BPSD are being cared for in the community by informal carers with the assistance from supports such as community care packages and respite. Caring for someone with BPSD can be stressful and can have significant impacts on both the mental and physical health of the carer. Both planned and emergency respite care are crucial components of support for carers and can enable individuals with dementia, including those with BPSD, to continue to live at home for as long as possible. It also provides individuals opportunities for social engagement and participation in appropriate and meaningful activities.

People living with dementia have difficulty accessing respite services that meet their needs. In the most recent Survey of Disability and Carers, 48% of primary carers of people with dementia reported that their main unmet need was respite care, whereas only 15% of all primary carers said that this was their main unmet need.<sup>24</sup> Only 27% of people with dementia approved for respite residential care use it within a year of their approval.<sup>25</sup>

The reasons for the underuse of respite are complex. Important contributory factors are that respite care is inflexible and is not available at the right time or provide insufficient hours of care. Consumers for their part may be reluctant to use a service because there is no perceived benefit for the person with dementia. Service providers may feel unable to provide and appropriately support individuals with BPSD. Family carers report that once the person with dementia develops BPSD services refuse to continue providing support<sup>26</sup> (see case study 2). Many of these problems stem not only from a lack of resources and appropriate staff training in care for people with BPSD but a culture where there is an inadequate commitment to meet the needs of the carer and person with dementia.

**Case Study 2:** This case study was told by Judy, wife and carer of Paul who had younger onset dementia and BPSD in regional Victoria.

“As Paul’s dementia deteriorated the service provider withdrew Paul from a Men’s Group because he was wandering, could not sit still and was a danger on the bus. The Planned Activity Group had mentioned that they were also finding it difficult and I felt it was only a matter of time before they would have to withdraw their services also. Weekend respite was reduced to one weekend a month because of similar issues and the provider felt Paul could not be accommodated with other people. An Aged Care Assessment Services assessment deemed Paul with high care needs so I investigated respite for high care. I contacted facilities advertising high care respite provision only to be told that no high care respite beds were available because they were all used by permanent residents, however low care respite beds were available. Paul was placed into permanent residential care. I could have kept him at home longer if there was adequate high care respite.”

Judy was subsequently dissatisfied with the treatment of Paul’s BPSD and removed him from residential care. She struggled to care for him at home until he passed away.

*-Provided by AAVIC Consumer Advisory Committee member*

There is a need for dementia specific respite services that can provide specialised care and support to people with BPSD. The development of specialised services could be resourced through a dementia supplement similar to the supplement provided in community care packages. Services which provide respite to clients who have dementia supplement would be required to show they were providing appropriate care including having staff with appropriate training and qualifications and appropriate staff to patient ratios required to support individuals with BPSD. The services should also be required to show they have ongoing consultation with clinical specialists to support care for individuals with BPSD.

## **Recommendation 2**

**As with the provisions for community care services, individuals with dementia should be eligible for a 10% dementia respite supplement. This additional funding should be used by providers to ensure appropriate care for individuals with BPSD.**

### ***2.3 Access to Clinical Support and Specialists***

Dementia and Behaviour Management Advisory Service (DBMAS) provides clinical support to aged care providers and family carers who are caring for someone with mild to severe BPSD. The role of the DBMAS programs is to improve the capacity of family carers, care workers, and service providers to respond to BPSD. Strategies DBMAS use to improve BPSD care and management include provision of information and advice, undertaking assessments and case management and the delivery of tailored information and education workshops to staff. Furthermore, DBMAS aims to support people from Culturally and Linguistically Diverse (CALD) backgrounds by providing translation and interpreting services, and behaviour consultants who have undertaken cultural sensitivity training and can provide advice on specific cultural resources related to dementia.

The new Aged Care reform, *Living Longer. Living Better*, includes funding for the expansion of DBMAS to include the support of people with BPSD in primary care and acute care.<sup>27</sup> This will greatly expand the scope of DBMAS to support a range of health professionals to improve their care for people with BPSD. The funding proposed in aged care reform package is not sufficient to cover the cost of this expansion and the increasing number of people with dementia within the Australian population.<sup>28, 29</sup> There is a need for increased funding and resources for DBMAS to ensure they can effectively support family carers, residential care, primary and acute care.

### **Recommendation 3**

**Double the current financial resourcing for DBMAS over the next three years to ensure that the service can adequately support family carers, residential, primary and acute care.**

## ***2.4 Staffing/Training***

Health care workers, including GPs, nurses, care staff, and allied health professionals all play a key role in preventing and responding appropriately to BPSD. Training in the use of non-pharmacological approaches to prevent and respond to behaviours is particularly important in ensuring appropriate care for individuals with BPSD.

There has been an increase in the proportion of individuals in residential aged care who require high level care. Between 1998 and 2011, the proportion of permanent aged-care residents classified as high care rose from 58% to 76%, with 48% having high care needs in the behaviour domain.<sup>30</sup> Despite an increase in high care patients and operational places, the number of registered and enrolled nurses working in aged care facilities has decreased significantly over the same period of time. This decrease in registered nurses has happened in the context of up-skilling of care workers with approximately two-thirds of personal care assistants (PCAs) having a Certificate III in aged care and 20 per cent a Certificate IV.<sup>31</sup>

In many cases, despite holding specific qualifications, health care workers have not received sufficient training in dementia care and preventative or appropriate responses to BPSD. Training in non-pharmacological approaches to BPSD is not included as a mandatory requirement in the certificate 3 or 4 in aged care or within the nursing or medical disciplines. The lack of sufficient training is illustrated by the fact that dementia training was reported as the most needed area of training in residential care by 42% of Registered Nurses, 37% of Enrolled Nurses and 53% of PCAs.<sup>32</sup> Research suggests that only 25% of residential aged care staff receive any training in dementia care.<sup>33</sup>

With the rapid increase in residents who have high care needs, staff need to have the training to respond appropriately to these care requirements. DBMAS has the capacity to provide training to aged care staff on BPSD and online training resources are also available online through the Dementia Training Studies Centres. Non-pharmacological approaches to care needs to be integrated into the curriculum of all health care professionals who work within the aged care sector.

## Recommendation 4

**Ensure that all health workers in the aged care sector have appropriate training in BPSD and non-pharmacological interventions. This should include training on psychosocial approaches to prevent and respond to BPSD in medical student, nursing and allied health academic programs and in all Aged Care Certificate 3 and 4 programs.**

### *2.5 Quality Care*

Behavioural and psychological disturbances are often an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear).<sup>34</sup> Environmental factors can also contribute to BPSD including too much stimulation, lack of privacy or an institutionalised like environment. Staff practices may also provoke behaviours, for example as noted above four staff approaching to remove a pad, dragging a person into the shower and startling the person. In many cases BPSD can be prevented through effective management of these contributing factors.

Comprehensive assessment and a focus on learning the language of dementia – observational techniques to assess how the person communicates pain – should be the required first step before any pharmacological treatment is prescribed. GPs should refuse to prescribe drugs for behaviours until nurses are able to provide the evidence that a full assessment has been undertaken to pinpoint any unmet need. Non pharmacological therapies, such as psychosocial and behavioural interventions, should be used as the first treatment approach to reduce the frequency and severity of BPSD and thereby reduce the need for restraint.<sup>35</sup> These interventions typically include the assessment of medical conditions, pain and communication and environmental issues, which sometimes underpin the development of BPSD.

There is emerging evidence that restorative and rehabilitative approaches to care for people with dementia may assist with BPSD.<sup>36</sup> Active restorative and rehabilitative activities, such as recreational and daily living activities have been associated with improvement in mood and behaviour.<sup>37</sup>

Care plans should be developed for each resident which identify the specific needs and corresponding approaches being used to address the particular behavioural symptoms for each resident experiencing BPSD. These care plans should be reviewed at least daily until the behaviour settles and whenever there is a change in behaviour. Residential aged care facilities should have links with dementia specialists and mental health services to assist in the review and development of appropriate care plans. The use of medications to treat behaviours should also be reviewed regularly by an interdisciplinary committee including the GP and pharmacist to ensure they are used appropriately.

Design of aged care facilities can play an important role in preventing the escalation of BPSD.<sup>38</sup> Facilities should be designed to reduce noise and other unwanted stimuli and reduce confusion. Other design features such as signage and cues, single bedrooms, secure indoor and outdoor areas for wandering and a homelike, familiar atmosphere can be helpful in providing a dementia friendly environment.<sup>39</sup> Thus, residential aged care facilities should undertake an internal environmental audit to identify environmental issues that may

be contributing to behavioural symptoms and should take reasonable steps to address the issues which are identified in order to improve care.

Some aged care facilities are taking appropriate steps to provide quality care for individuals with BPSD. Many are not. As a result there are still numerous reports of physical and chemical restraint.<sup>40</sup> Information on quality of care for people with dementia should be provided through the quality indicators on the new “My aged care” website and further consideration should be given to how quality care can be linked to resourcing and other incentives. In addition, consideration should be given to how the Aged Care Accreditation process can be strengthened to ensure higher quality care for individuals with BPSD.

## ***2.6 Resourcing in Aged Care***

One of the challenges of providing appropriate care to individuals with BPSD is it requires high levels of support and is resource intensive. Consumers often report difficulty in accessing appropriate community services and residential aged care facilities as they are told that the service does not have sufficient resources to provide the high level of care required, which occurred in case study 2. The ***Living Longer. Living Better.*** aged care reforms begins to address these concerns through a program of supplements in both community and residential care.

### *Community Care*

In community care, a dementia supplement will be available that is based on cognitive impairment (not presence of BPSD) and provides an additional 10% of the total package of care to cover the additional costs of caring for a person with dementia. The highest level of home care package with a dementia supplement will almost be equivalent to the current Extended Aged Care at Home –Dementia (EACH-D) package.

Although the supplement in community care will provide important additional resources, there will still be many consumers who are forced to turn to residential aged care for support as the level of resourcing in community care is not sufficient. In part this is because only approximately one-third of community packages will be available at the highest level, and because even at the highest level, packages do not offer sufficient support for those with complex support needs.<sup>41</sup> It is estimated, for example, that an EACH-D package provides direct care for an average of 14 hours per week.<sup>42</sup> For individuals with BPSD or other high care needs this often does not provide enough support for them to remain in the community.

### *Respite*

Aged care reform has not addressed the need to appropriately resource respite services to provide care for individuals with BPSD. As previously discussed, there is a need for dementia care supplements within respite services, similar to the supplement funding for community aged care packages, to ensure that respite services can cater for people with dementia. This issue is addressed in **Recommendation 2**.

## *Residential Care*

The Aged Care Funding Instrument (ACFI) has not captured the additional costs of providing care for individuals with the most severe and frequent BPSD. The aged care reforms, however, recognise the extra costs of caring for those with more severe behaviours through a proposed dementia supplement in residential care for these individuals. This supplement will help to match funding with extra care needs required for people with mild to severe BPSD. This funding should improve the support and care individuals with BPSD obtain and increase the time for psychosocial interventions, appropriate social engagement and activities.

The details of this supplement are currently subject to consultation by the Department of Health and Ageing. There is concern that the supplement may not lead to better care for individuals with BPSD if it is not linked to quality of care. Instead aged care facilities would have an incentive to accept individuals with high behaviour needs regardless of whether they had the appropriate staff or facilities to provide good care. The supplement should be linked to specific requirements for providers to show that they have the capacity to provide appropriate care.

In cases of severe or extreme BPSD mainstream models of aged care may not be able to provide appropriate care even with the additional supplements and better resourcing. Different models such as matching mental health funding and services with aged care may be required for these groups and this is considered in more detail in the next section.

### **Recommendation 5**

**The dementia behaviour supplement in residential care should only be provided to aged care facilities that can document that they are able to provide high quality care for individuals with severe BPSD. This should include:**

- **Identifying a person within the facility as the behaviour program coordinator. This person would be responsible for identifying staff training needs, ensuring access to appropriate materials and resources, coordinating access to specialist clinicians with expertise in behaviours and ensuring standards are met.**
- **A commitment to using no physical restraint except in cases of immediate danger for self or others and document action taken and how soon the restraint has been removed.**
- **Documentation of a comprehensive assessment to identify any untreated medical cause of behaviour and to identify any unmet needs and action taken to address those needs.**
- **An environmental self-audit using a validated tool and evidence to show reasonable steps have been taken to address issues identified through the audit.**
- **A regular review of the program (including use of restraint and medications, care outcomes, issues around seclusion).**



### 3. SPECIALISED CARE AND SUPPORT

#### *3.1 Interface of Mental Health and Aged Care*

Individuals with severe BPSD who are ambulant often require specialised care. The care required by this group overlaps considerably with older individuals who have behavioural and psychiatric symptoms related to mental health conditions. Both groups require access to specialised 'psycho-geriatric care', although the underlying cause of their symptoms may be different. The National Health and Hospital Reform Committee (2009) identified access to psycho-geriatric care as an area that needs reform. "As a matter of some urgency, governments must collaborate to develop a strategy for ensuring that older Australians, including those residing in aged care facilities, have adequate access to specialty mental health and dementia care services".

The issue has been well documented in work done by the Department of Health and Ageing and for the Ministerial Conference on Ageing in December 2010. In the report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders in 2008<sup>43</sup> a number of important recommendations were made to better meet the complex care needs and behaviours of this group. The only response was to commission two projects to demonstrate how care for this group could be better delivered, even though it is arguable that there is already sufficient knowledge to identify the strategies that would enable the aged care and mental health systems to do better.

The report of the Psychogeriatric Care Expert Reference Group was considered by the Ministerial Conference on Ageing in 2009.<sup>44</sup> It carefully documented a framework for service planning and care delivery for people with psychogeriatric disorders. The framework included:

- i. Integration at all levels within the broader health care system with appropriate facilities to assist older people with BPSD and/or mental health issues.
- ii. Ongoing access to and utilisation of specialist clinical expertise and care.
- iii. Appropriate assessment mechanisms and placement to ensure best 'client fit'.
- iv. Appropriate staff levels and skills mix across the continuum of care.

The Ministerial Conference endorsed that framework.<sup>45</sup>

Within limited resources priorities have to be set and to make a start in addressing what have been the long standing concerns of consumers we suggest two strategies.

##### *1. Specialised Units*

First, the establishment of specialised high care dependency units which are designed to meet the needs of individuals with severe BPSD and individuals with severe mental health concerns has been identified as the preferred approach<sup>46</sup>. These units have appropriately trained staff and access to specialised clinicians and work to stabilise the individual so that they can be returned to mainstream services.

Individuals who require psychogeriatric care are often unable to access care that addresses both their aged care and mental health needs because of structural barriers between the state-funded mental health system and the Commonwealth funded aged care system<sup>47</sup>. These barriers and lack of adequate funding have led to a shortage of specialist facilities.

Some states provide specialised care through aged care facilities that are funded through the Aged Care Act and are topped up with funding from the State Government to provide high levels of mental health support<sup>48</sup>. This system may work well in some states, but in others there is a clear lack of collaboration and a gap in services. As a result, there is a need to clearly identify who is responsible for the care of older individuals with mental health needs. Examples of this approach include the Psychogeriatric Nursing Homes in Victoria, and Psychogeriatric Care Units in Western Australia.<sup>49</sup> These facilities use ongoing behavioural assessment and rehabilitation, with the goal to discharge residents to mainstream facilities.

The Psychogeriatric Nursing Homes in Victoria have been established in each health region and are designed to operate as longer term transitional care models, with clients being relocated to less intensive service options when appropriate.<sup>50</sup> These nursing homes have strict admission and discharge criteria and close relationships with acute and community-based service providers through the Aged Psychiatric Assessment and Treatment Teams. These teams provide assessment, case management, referral and access to support across the entire mental health services.<sup>51</sup>

## *2. Access to appropriate specialist teams within Residential Aged Care*

A second strategy is to ensure that individuals who are receiving care in main stream services have access to appropriate specialist mental health care as needed. This is discussed earlier in the submission with regards to quality of care and access to specialist support. The goal should be to provide the best quality care and to involve an interdisciplinary team that has the appropriate qualifications to provide the psychogeriatric care required.

## **Recommendation 6**

**Federal and State Governments should work together as part of their commitment to dementia as a national health priority to development and implement specialised community neurobehavioural units which provide specialised mental health services for individuals with the most severe behaviours through matching aged care and mental health funding and services.**

## ***3.2 Acute Care***

For people with dementia, being admitted to hospital can be a confusing and frightening experience. Hospitals are noisy, unfamiliar environments, which can create confusion and distress for individuals with dementia, leading to more frequent and more severe episodes of BPSD in some people. It is estimated that up to 95% of people with dementia in long term acute care have some form of BPSD.<sup>52</sup>

Adverse outcomes are often experienced by individuals with dementia during their stay at hospitals, including physical and cognitive functional decline, under-nutrition, skin tears and

fall-related injuries. Overall, this leads to delays in recovery and a longer length of stay for the individual.<sup>53</sup> Recent estimates from New South Wales show that people with dementia stay in hospital almost twice as long as those without dementia, averaging 16.4 days of care compared with 8.9 days for other patients.<sup>54</sup>

There is evidence to suggest that in many cases hospitalisation of individuals with dementia can be prevented through better management of health conditions, and palliative approaches to care. There is a need for a multi-faceted integrated approach between hospital, mental health services, residential aged care facilities and community services to ensure that individuals with dementia receive care in the most appropriate environment.<sup>55</sup>

Approximately a quarter of people with dementia in hospitals experience delirium, and acute confusional state.<sup>56</sup> Assessment and appropriate management of delirium in hospital is an important component to responding to BPSD. Behavioural units within hospitals can help better manage and care for people with BPSD and those with delirium within the acute setting. These units focus on behavioural and environmental approaches to care and involve multidisciplinary teams who specialise in BPSD. Staff develop relationships with patients and become familiar carers, which reduces agitation and aggression. Other key features of specialised behavioural units include secure ward environments that contain minimal noise and stimuli and support safe mobilisation.<sup>57</sup>

Liaison psychiatry services in acute care can also play an important role in managing the mental health needs of people with dementia. These services generally consist of a multidisciplinary team that offer a comprehensive range of mental health specialities so that BPSD patients can be assessed, treated, signposted or referred appropriately. Hence, psychiatric services can have a wide range of positive outcomes for the patient, staff and health-care provider.

## **Recommendation 7**

**Introduction of systems, to reduce unnecessary hospitalisations of people with dementia and to ensure that if hospitalised, individuals with BPSD have access to quality care in an appropriate environment and staff who have training in non-pharmacological approaches to care.**

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