

HEALTH AGEING AND HUMAN SERVICES

Ministerial Dementia Forum— Options Paper

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MANAGEMENT CONSULTING

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Executive summary

Dementia is the gradual, progressive and irreversible decline in brain function. It is a syndrome, meaning it is characterised by multiple symptoms which may include difficulties with language, memory, perception, changes in personality and reduced cognitive skills. It can result from one, or a combination of over 100 identified causes, the most common of which are Alzheimer's disease and vascular disease. With age as the major non-modifiable risk factor, the prevalence of dementia approximately doubles every five years beyond the age of 65 and for those aged 85 and over, the prevalence is approximately one in every four persons.

With Australia's ageing population, it is important that the Australian Government provides appropriate levels of support for people with dementia; their carers and family; and aged care service providers to ensure that people with dementia receive high quality care.

Following the Australian Government's decision to cease the Dementia and Severe Behaviours Supplement in June 2014, the Assistant Minister for Social Services Senator the Hon Mitch Fifield and the Minister for Health the Hon Peter Dutton MP held the Ministerial Dementia Forum, 'Dementia Care – Core Business for Aged Care', on 11 September 2014 in Melbourne. Seventy participants from across Australia representing service providers, clinicians, carers, people with dementia and the government attended the forum. The purpose of the forum was to identify what is currently working well, areas for improvement, potential policy options to address the care needs of people with dementia and experiencing severe Behavioural and Psychological Symptoms of Dementia (BPSD).

This paper captures the feedback provided on the day by the forum's participants, as well as submissions provided by participants subsequently. The future reform options cover a wide range of topics including consumer engagement; education and training; unmet needs; specialised support; quality of life indicators; and funding. Each option that was presented has been developed further, with an assessment of the benefits, risks and feasibility.

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1. Background

Dementia is the gradual, progressive and irreversible decline in brain function. It is a syndrome, meaning it is characterised by multiple symptoms which may include difficulties with language, memory, perception, changes in personality and reduced cognitive skills.¹ Dementia can result from one, or a combination of, over 100 identified causes, the most common of which are Alzheimer's disease and vascular causes.² Its progression can be categorised into four phases:

- early difficulties (the pre-diagnostic phase)
- the emergence of significant difficulties in daily living
- a reduced capacity for independence
- incapacity and a high dependence on care.³

With age as the major non-modifiable risk factor, the prevalence of dementia approximately doubles every five years beyond the age of 65.⁴ Amongst those aged 85 and over, the prevalence of dementia is approximately one in every four persons.⁵ As a result of the ageing population, the prevalence of dementia is expected to grow from 332,000 in Australia in 2014 to 550,200 people by 2030, and 891,400 people by 2050.⁶

According to the Australian Institute of Health and Welfare, over 50 per cent of permanent residents within Australian Government-funded aged care facilities have a diagnosis of dementia.⁷ In 2009-10, two billion dollars of expenditure was attributable to dementia, of which over half was represented by residents within residential aged care facilities.⁸ People with dementia are more likely to have longer lengths of stay due to having to enter residential care earlier in their lifespan, as well as being more likely to have higher level complex care needs, including BPSD.

BPSD can be mild or severe, with symptoms including 'disturbed perception, thought content, mood or behaviour including aggression, apathy, anxiety, agitation, psychotic symptoms, depression, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours'.⁹ People with severe BPSD present significant challenges for residential care providers

¹ Australian Institute of Health and Welfare (AIHW) 2012, Dementia in Australia, catalogue no. AGE 70, AIHW, Canberra.

² AIHW, Dementia, viewed September 2014 [Australian Institute of Health and Welfare \(http://www.aihw.gov.au/dementia/\)](http://www.aihw.gov.au/dementia/)

³ KPMG 2011, Dementia services pathways – an essential guide to effective service planning, [KPMG \(http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm/\\$FILE/Dementia-services-pathways\(ext2\).pdf\)](http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm/$FILE/Dementia-services-pathways(ext2).pdf)

⁴ AIHW 2004, The Impact of dementia on the health and aged care systems, catalogue no. AGE 37, AIHW, Canberra.

⁵ AIHW 2012, Dementia in Australia, catalogue no. AGE 70, AIHW, Canberra.

⁶ AIHW 2012, Dementia in Australia, catalogue no. AGE 70, AIHW, Canberra.

⁷ AIHW, Dementia, viewed September 2014 [Australian Institute of Health and Welfare \(http://www.aihw.gov.au/dementia/\)](http://www.aihw.gov.au/dementia/)

⁸ AIHW 2012, Dementia in Australia, catalogue no. AGE 70, AIHW, Canberra.

⁹ Department of Health and Ageing 2013, submission to Senate Standing Committee on Community Affairs' Inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD), p. 6.

but symptoms can be episodic relating to specific physical, social or environmental unmet needs. If these needs are met then symptoms may subside.

Treatment and severity of BPSD is usually assessed in Australia via the Brodaty Triangle, a seven tiered model of service delivery for BPSD which provides an evidence-based practice model of management. People at the bottom end of the spectrum, with less developed signs and symptoms, receive the least intervention, while people at the top end of the spectrum, with further developed symptoms, receive the most.¹⁰

1.1 Dementia supports in place

Currently the Australian Government has the following programs and services in place to meet the objective of better practice in dementia care:

Dementia Behaviour Management Advisory Services

The Dementia Behaviour Management Advisory Services (DBMAS) provide advice and support to those caring for people with dementia. Services may include clinical advice over the phone, assessment, care plan development, mentoring and education and training. DBMAS staff are accessible over the phone via a 24 hour helpline and cater for aged care workers as well as family carers.¹¹

National Dementia Support Program

The National Dementia Support Program (NDSP) is an Australian Government funded initiative delivered by Alzheimer's Australia and was formed as a consolidation of previously run programs aimed at dementia support. NDSP delivers a helpline and referral service, dementia and memory community centres, early intervention support, non-clinical advice, counselling and professional support, education and training, special needs support, as well as serving an awareness function.¹²

Dementia Training Study Centres

Dementia Training Study Centres (DTSCs) provide courses, workshops and seminars for continuing professional education for dementia health care professionals and students as well as assisting universities with curriculum development.¹³

Service Access Liaison Officer

Additional funding was allocated to Alzheimer's Australia via the NDSP to provide Service Access Liaison Officers (SALOs) in each state and territory throughout Australia to address barriers to access for specific needs groups. SALOs aim to provide access to dementia services to Aboriginal and Torres Strait Islander people; people from Culturally and Linguistically Diverse backgrounds;

¹⁰ Brodaty H, Draper, B & Low, LF 2003, Behavioural and Psychological Symptoms of Dementia: A Seven Tiered Model of Service Delivery, Medical Journal of Australia, vol. 178, pp 231 – 34

¹¹ Dementia Behaviour Management Advisory Services, viewed September 2014, [DBMAS \(http://dbmas.org.au/what-we-do/who-is-eligible/\)](http://dbmas.org.au/what-we-do/who-is-eligible/)

¹² Grenade, L., Williams, P., Horner, B., & Carey, M. 2007, Evaluation of the National Dementia Support Program (NDSP) Report, viewed September 2014, [Evaluation of the National Dementia Support Program \(https://fightdementia.org.au/sites/default/files/20120730_NAT_Final_Evaluation_Report15Feb07.pdf\)](https://fightdementia.org.au/sites/default/files/20120730_NAT_Final_Evaluation_Report15Feb07.pdf)

¹³ Dementia Training Study Centres, viewed September 2014, [DTSC \(http://www.dtsc.com.au/\)](http://www.dtsc.com.au/)

Gay, Lesbian, Bi-Sexual, Transgender and Intersex people; people with Younger Onset Dementia; and people in rural and remote locations. SALOS' projects have been focused on raising awareness and reducing stigma, as well as enhancing services' ability to meet the needs of these groups.

Dementia Education and Training for Carers

The Dementia Education and Training for Carers (DETC) programme is Australian Government funded and delivered via the Commonwealth Respite and Carelink Centres. DETCs provide carers with early intervention support, including in-home and group education as well as providing help in linking carers to other available resources depending on their individual needs. DETCs aim to improve care services for people with dementia by increasing the competence and confidence of carers and providing more support for timely diagnosis.¹⁴

Younger Onset Dementia Key Worker Programme

The Younger Onset Dementia Key Worker Programme provides individualised information and support to improve the quality of life for people with younger onset dementia. The key worker acts as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling, advice and helps consumers effectively engage with services appropriate to their individual needs.¹⁵

The Dementia and Cognition Supplement in Home Care

The Dementia and Cognition Supplement in Home Care is available to home care recipients who are assessed as having moderate to severe cognitive impairment. The supplement is paid at the rate of 10 per cent of the basic subsidy payable for each of the four levels of Home Care Package and is indexed annually.¹⁶

1.2 Additional supports

The Commonwealth funds a range of other support for older people accessing aged care. These are also available for people with dementia.

Aged care assessment teams

Aged care assessment teams or services (ACATs/ACAS) assess a consumer's eligibility for government subsidised residential and home care aged care services. This assessment can help people with dementia to identify the type of care services that will help them stay at home, receive certain respite services or to enter into an aged care facility.

¹⁴ Department of Health, Support for people with dementia, their families and carers, viewed September 2014, [Department of Health \(http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-support\)](http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-support)

¹⁵ Alzheimer's Australia, Fight Dementia, National Younger Onset Dementia Key Worker Program, viewed October 2014, [Alzheimer's Australia \(https://fightdementia.org.au/support-and-services/services-and-programs-we-provide/national-younger-onset-dementia-key-worker-program\)](https://fightdementia.org.au/support-and-services/services-and-programs-we-provide/national-younger-onset-dementia-key-worker-program)

¹⁶ Department of Social Services, Ageing and Aged Care, viewed October 2014, [Department of Social Services \(http://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/aged-care-reform/get-involved/dementia-and-cognition-supplement-in-home-care-and-the-dementia-and-severe-behaviours-supplement-in-residential-care-0\)](http://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/aged-care-reform/get-involved/dementia-and-cognition-supplement-in-home-care-and-the-dementia-and-severe-behaviours-supplement-in-residential-care-0)

National Aged Care Advocacy Program

Operating in each of the states and territories, the National Aged Care Advocacy Program (NACAP) provides advice and help to people with dementia and carers to understand and exercise their rights. NACAP also acts on behalf of people with dementia and carers in discussions within the aged care industry in policy formation.¹⁷

Community Visitors Scheme

Referred by family, friends or service provider managers,¹⁸ the Community Visitors Scheme (CVS) matches volunteers to socially isolated people in residential aged care facilities for companionship and social engagement.¹⁹

1.3 Accreditation and funding of aged care organisations

Aged care accreditation

There are 44 expected outcomes across four standards in residential aged care, and 18 expected outcomes across three standards for home care providers. These are based on the *Quality of Care Principles 2014*, issued by the Assistant Minister as permitted by sections 96-1 the *Aged Care Act 1997*,²⁰ and the expected outcomes are required for accreditation and quality review of residential aged care facilities, and home care providers respectively.

Residential facilities are reviewed periodically using standard audit methodology which systematically reviews all 44 expected outcomes. Failure to meet the outcomes will result in the submission of a timeline of improvement, after which further noncompliance can result in accreditation being revoked or other sanctions.²¹

Aged Care Funding Instrument

The Aged Care Funding Instrument (ACFI) is a tool designed to align allocation of funding with needs. It assesses people's care needs on the basis of their diagnoses, and assessed level of assistance required or level of impairment across the domains of activities of daily living; behaviour; and complex care needs. People are assessed using approved validated instruments to determine a low, medium or high level.²²

¹⁷ Department of Health, The National Aged Care Advocacy Program, viewed September 2014, [Department of Health \(http://www.health.gov.au/agedcareadvocacy\)](http://www.health.gov.au/agedcareadvocacy)

¹⁸ Department of Health, Information on Community Visitors Scheme for consumers, viewed September 2014, [Department of Health \(http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-rescare-cvs-cvscons.htm#referral\)](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-rescare-cvs-cvscons.htm#referral)

¹⁹ Department of Health, Community Visitors Scheme, viewed September 2014, [Department of Health \(http://health.gov.au/cvs\)](http://health.gov.au/cvs)

²⁰ ComLaw, Quality of Care Principles 2014, Commonwealth Government of Australia, viewed September 2014, [ComLaw, Australian Government \(http://www.comlaw.gov.au/Details/F2014L00830/Explanatory%20Statement/Text\)](http://www.comlaw.gov.au/Details/F2014L00830/Explanatory%20Statement/Text)

²¹ Australian Aged Care Quality Agency, Failure to meet the Standards, viewed September 2014, [Australian Aged Care Quality Agency \(https://www.aacqa.gov.au/for-providers/failure-to-meet-the-standards\)](https://www.aacqa.gov.au/for-providers/failure-to-meet-the-standards)

²² Department of Health, Using the Aged Care Funding Instrument (ACFI), viewed September 2014, [Department of Health \(http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-acfi-using.htm\)](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-acfi-using.htm)

1.4 Addressing behavioural and psychological symptoms of dementia

In order to assist residential aged care providers in addressing the needs of residents with severe BPSD, the Australian Government introduced the DSBS of \$16.15 per day per eligible resident in August 2013.

It was estimated that 2,000 aged care residents would be eligible for the DSBS in 2013-14 with a budgeted expenditure of \$11.7 million. As of April 2014, 29,927 people were receiving the DSBS with an estimated actual cost of approximately \$110 million in 2013-14. As a result of far higher than expected claiming, the Australian Government ceased the DSBS on 31 July 2014.

2. Our approach

The Assistant Minister for Social Services Senator the Hon Mitch Fifield and the Minister for Health the Hon Peter Dutton MP committed to a forum to look at dementia as 'core business' across aged care and, as part of that, to consider alternatives to the Supplement. The Department of Social Services (DSS) Ageing and Service Improvement Branch engaged consultants to conduct and report on the Ministerial Dementia Forum aimed at undertaking broad stakeholder consultation on possible future directions in improving dementia care. The Ministerial Dementia Forum, 'Dementia Care – Core Business for Aged Care', was held on 11 September 2014 with 69 participants from across Australia representing service providers, clinicians, carers and people with dementia and the Australian Government (See Appendix 1 for a list of the participant organisations). The forum was Co-Chaired by Associate Professor Susan Koch and Ms Sue Pieters-Hawke.

The overarching aim of the day was to establish what is needed to improve the provision of dementia care both in residential aged care and home care, whilst remaining within the current funding envelope. The discussions were built on the following four objectives:

- **Objective one:** improve and promote the wider adoption of better practice care and support of people with dementia within the aged care system both in residential care and care and support in the home.
- **Objective two:** consider effective models of care and support for people with severe BPSD and dementia within the aged care system, both in residential care and care and support in the home, and examine ways to promote them.
- **Objective three:** explore strategies that facilitate and consolidate dementia care as 'core business' for all aged care services.
- **Objective four:** explore models of care that provide timely and cost effective specialised support for care of people with dementia with complex needs or severe BPSD, including for particular populations with special needs.

Senator the Hon Mitch Fifield, Professor Henry Brodaty, Ms Kate Swaffer, and Dr Stephen Judd gave short addresses in order to identify the Government, clinician, consumer and service provider perspectives, on dementia, respectively. This was followed by three workshop sessions, involving round table discussions amongst the table groups, with the key findings presented to the broader group. The three workshop sessions answered the following questions:

- 1) When it comes to supporting people with dementia, what is working in the current system? Where is there opportunity for improvement? What is needed in the short, medium and longer term?
- 2) Within the current funding envelope, how would you address the need to assist residential aged care consumers with dementia and severe BPSD? Consider opportunities in the short, medium and longer term.
- 3) What needs to be done specifically for people with severe BPSD within the available budget envelope? What is needed in the short, medium and longer term?

Each table had a scribe to capture the key ideas within the discussions. Following the day, scribes reports were sent to table captains for verification, after which theme analysis was undertaken to

inform this report and the options within it. A summary of the workshop sessions is outlined in Sections 3 and 4, with potential next steps identified in Section 5.

A small working group Co-Chaired by Associate Professor Susan Koch and Sue Pieters-Hawke helped design the forum and work with the facilitator to prepare this paper for the consideration of the Assistant Minister for Social Services, Senator the Hon Mitch Fifield, and the Minister for Health, the Hon Peter Dutton MP.

3. Current state of dementia care

3.1 What is working well

Participants identified what is currently working well in the care of people with dementia within residential and home care. The key themes from these discussions are identified below. It is important to note that when discussing what was working well, participants often identified associated challenges with that particular topic. Participants almost universally agreed that the aged care sector's understanding and destigmatisation of dementia is improving but there is still room for further improvement.

A committed workforce

The Australian aged care workforce is comprised of workers with strong goodwill in delivering high quality care to their residents/clients. At the forefront of clinical and personal care, the aged care workforce do their best to ensure that the best outcomes are achieved for their residents/clients. This also extends to the leadership of many service providers who are committed to driving improved outcomes and trialling new approaches.

Current support programs

Australia's proactive and innovative approaches to improving dementia care were acknowledged, with participants recognising spending in dementia and development of programs had expanded significantly over the past two decades. However, it was identified that there is still a lot more improvement to be made, and that the focus and innovation has been fragmented and lacks any consistent direction. As a consequence, benefits of these innovations have not been widely shared across the aged care sector.

Amongst the strategies and initiatives that are currently funded by the Australian Government, a number were identified as working well within parts of the aged care sector. This included DBMAS and DTSCs, which are working well to support the delivery of appropriate care in residential aged care facilities. However, there are issues regarding effectiveness across the sector, and access, particularly in rural and remote areas.

It was reported during the workshop that evaluation feedback from DBMAS programs report improved staff capacity and confidence in managing clients with dementia. However, it was cautioned that programs such as DBMAS work best in an ongoing supporting role rather than as an emergency response mechanism to assist those with severe BPSD.

Training and education

Participants identified many high quality training and education opportunities currently available. Where these were implemented and applied well, it had a significant impact on wellbeing and care of people with dementia. However, several participants noted the education landscape was difficult to navigate, and there was a lack of formal recognition amongst participants around what was available.

As noted above, participants thought that training and education provided by DTSCs was of great assistance in improving the skills of staff working with people with dementia. Participants did, however, think that more work needed to be done, including by DTSCs, on disseminating and translating the lessons of research into practice.

Consumer-directed care

Consumer-directed care (CDC) is a way of delivering services that allow consumers to have greater control over their own lives by enabling them to make choices about the types of care and services they access and the delivery of those services.²³ CDC packages for home care have been piloted by the Australian Government and shown to have several positive impacts such as increased satisfaction amongst package recipients and their carers'.²⁴ CDC is currently being implemented for all new home care packages, commencing from 1 July 2014 with existing packages being transferred to CDC on 1 July 2015. As part of its aged care reforms, the Australian Government has announced that CDC will be trialled in residential care.

Some participants identified that home care packages delivered by CDC, where people with dementia (or their carers/legal guardians) can tailor their care to their personal needs, were reported to be working well and delivering better outcomes for people with dementia.

3.2 Key challenges

Forum participants identified key challenges for the sector in the provision of care for people with dementia within residential or home care. These are outlined below.

Stigma and social attitudes

Dementia is a social as well as a medical condition. People living with dementia frequently observe that from the moment of diagnosis they have experienced social isolation and stigma. It was noted at the forum that while society generally supports people who suffer other debilitating diseases in their attempts to return to their normal lives, the attitude towards people with dementia is often not as supportive. This issue ties in with the need to build dementia friendly communities that are more accommodating to the greater difficulties faced by people with dementia living in the community.

Consumer engagement

One of the key issues identified at the forum was the lack of consumer engagement on decision making within dementia care. People with dementia are often not consulted in the design and implementation of policy initiatives. Another challenge is that dementia is an umbrella term for a wide range of diseases with the consequence that the experience of dementia varies widely, both from person to person and as the disease progresses.

Consumer choice

Participants thought that more information for people with dementia and their carers about the services offered by different aged care providers would be helpful. It was thought that the information being provided on the MyAgedCare website was a good step in the right direction, and

²³ Department of Health, Consumer Directed Care - Evaluation of Pilot Program, viewed September 2014, [Department of Health \(http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cdc-evaluation-pilot-program\)](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cdc-evaluation-pilot-program)

²⁴ KPMG 2012, Evaluation of the consumer-directed care initiative – Final Report, for Department of Health and Ageing, viewed September 2014, [KPMG \(http://www.health.gov.au/internet/main/publishing.nsf/Content/F072F0C75198E936CA257BF0001A35BF/\\$File/DC-Eval-Final-Rep.pdf\)](http://www.health.gov.au/internet/main/publishing.nsf/Content/F072F0C75198E936CA257BF0001A35BF/$File/DC-Eval-Final-Rep.pdf)

something similar providing information on home care providers would be useful. It was also noted that geographic location (close to family and friends) remained the key determinant for many people when choosing residential care. Additionally, there was support from participants for trialling models of respite care funding following the care recipient rather than being allocated to providers.

Increased competition

Participants thought that increased competition amongst service providers would increase the sector's effectiveness in providing quality dementia care.

Unmet needs

Participants called for increased recognition that unmet need is an underlying cause of some people's BPSD, including severe BPSD. Recognition of the reversibility of many symptoms and behaviours, and a shift in thinking in identifying triggers and contributing factors towards a person's behaviour were raised during the discussions. Some people's behaviours can be triggered by specific issues such as pain, food allergies, catastrophic events and so on. Addressing these issues can lead to reductions in the incidence of severe behaviour and the need for physical or chemical restraint. Participants thought that identifying and addressing unmet needs would improve dementia care across the sector.

Specialised support

A lack of specialised support was identified as a significant problem by most forum participants. Providers often had challenges in accessing support for people with severe BPSD and/or had challenges in implementing strategies to support people with severe BPSD. The use of dementia specific units and 'flying squads' to complement DBMAS in supporting aged care homes to provide appropriate care was considered a good idea. Special support service models could be geriatrician, GP or nurse practitioner led, and involve specialised assessment and multidisciplinary input. These models could be applied both to the residential and home care domains and were considered to be highly effective where available.

Reach and variability of support services

Despite positive attitudes towards DBMAS participants thought that its reach was limited, particularly after hours and in rural and remote areas where it was reported there were significant challenges in accessing its services. It was reported that people with dementia and severe BPSD were often relocating to different geographic areas due to an inability to access sufficient support in their own communities. This created considerable difficulties for the person with dementia and their carers.

Participants also made similar observations concerning inconsistent reach and service provision for DTSCs across jurisdictions and expressed a desire for greater national consistency. It was also suggested that there could be greater collaboration between DBMAS and DTSCs to increase the level of specialist support available to individuals and service providers.

Access

It was acknowledged at the forum that people with dementia exhibiting severe behaviours may also be affected by other compounding factors such as homelessness which may further adversely affect their ability to access appropriate care.

Some participants also reported that ACATs/ACAS are hard to access, particularly for younger people with dementia, unless there is a crisis.

Education and training

An appropriately skilled and empowered workforce is required in order to proactively identify and respond to an individual's symptoms as a consequence of their unmet needs. It was noted that there is currently a perceived lack of structure around training and knowledge dissemination in dementia care. As identified previously there are significant benefits from training, and there are plenty of opportunities available for education and skills enhancement within dementia and severe BPSD, including training provided by DTSCs. However, there is currently no consistent national approach to this and it can be difficult to navigate.

Participants expressed that parts of the sector still had not completely embraced the aim of integrating dementia care as part of the 'core business' of the sector. There is also a need to create subspecialisation within the usual workforce within aged care organisations. This will help ensure both early intervention and follow-up, as well as sustained application of recommendations and ability to evaluate outcomes and modify treatment plans accordingly.

Accreditation and quality of life indicators

Participants expressed concern over the extent to which the accreditation process ensures quality of life for residents with dementia and severe BPSD. While participants recognised the value of quality standards and the need for accreditation, there was a view that there should be an increased focus on quality of life issues including through quality indicators.

Also, some participants thought there was scope to make the complaints system more user friendly for people with dementia and their families.

Funding

There were mixed views around ACFI. Some participants would prefer block funding models, while others felt the concept of distributing funding on the basis of needs was positive and that ACFI, although not a perfect system, went some of the way to achieving this end. There was support for ACFI to be included within a review of current dementia initiatives, however, this issue was outside the scope of the forum.

Leading Age Services Australia (LASA) acknowledged that the options recommended in the Report are a reflection of the discussions at the Dementia Forum. LASA representatives noted that in their view the options recommended in the report have the potential to divert the Dementia and Severe Behaviour Supplement (DSBS) into support programs that will not deliver an immediate outcome for residents currently requiring care, or for service providers who are stretched, when attempting to maintain a person in the current service without the DSBS that was previously provided to assist with additional resources for people with very severe behaviours of dementia. In LASA's view the removal of the supplement from residential aged care placed considerable stress on the sector and they would like the supplement funding reactivated in some form for the individual consumer and/or service provider. This was not the consensus view expressed by the forum nor endorsed by the working group.

Many participants also expressed a strong preference for funding to follow the consumer through their care journey, as will occur with the National Disability Insurance Scheme, rather than going to

the service provider as currently occurs in aged care. Additionally, there was support for a greater focus on reablement and minimising functional decline within the funding system. These issues were, however, also outside the scope of the forum and beyond the funding envelope.

4. Options

Throughout the forum, participants were not only asked to identify what is currently working well and what needs to be improved in the provision of dementia care both in residential aged care and home care, but to also identify potential solutions to the issues raised within the current funding envelope. The solutions were to take the form of policy options to address the care needs of people with dementia and those experiencing severe BPSD within the funding envelope, particularly within residential care. Participants were also provided with the opportunity to submit potential reform options to the consultants following the forum.

The potential options for reform covered a wide range of topics including consumer engagement; education and training; unmet needs; specialised support; accreditation; and funding. Further consideration will be required to determine the exact formulation of each option, the funding requirements, and implementation timing. The level of support for each of these options differed considerably with broad consensus around some potential options and less consensus around some others. This is not to say that the options that were not supported as widely are not worthy of further consideration.

The options presented below were considered by participants to improve the provision of dementia care both in residential aged care and home care, although some options are beyond the funding envelope and therefore would not be in scope. The table below indicates which of the four forum objectives below are satisfied by each policy option:

- **Objective one:** improve and promote the wider adoption of better practice care and support of people with dementia within the aged care system both in residential care and care and support in the home.
- **Objective two:** consider effective models of care and support for people with severe BPSD and dementia within the aged care system, both in residential care and care and support in the home, and examine ways to promote them.
- **Objective three:** explore strategies that facilitate and consolidate dementia care as 'core business' for all aged care services.
- **Objective four:** explore models of care that provide timely and cost effective specialised support for care of people with dementia with complex needs or severe BPSD, including for particular populations with special needs.

Table 1: Outcomes of policy options compared to the Ministerial Dementia Forum objectives

Strategy	Objective One	Objective Two	Objective Three	Objective Four
A	✓		✓	
B	✓	✓	✓	✓
C	✓	✓	✓	✓
D	✓	✓	✓	✓
E		✓		✓
F	✓		✓	
G		✓		✓
H	✓	✓	✓	✓

Source: KPMG

4.1 Consumer engagement

It is important to outline an option that was put forward at the forum, that the level of engagement with people with dementia and their carers needed to be increased. Greater representation of people with dementia and their carers at future annual Ministerial Dementia Forums and other policy discussions would ensure that the thoughts of the people who will be most affected by changes to dementia policy are included in future discussions.

Strategy	A. Increase consumer engagement
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 1 and 3.
Description	<p>Future Ministerial forums and other stakeholder consultation around dementia care should be expanded to include a greater representation from people with dementia and their carers'</p> <p>There could also be increased focus on providing consumers with better information and access to the latest research on dementia and developments within the sector.</p>
Benefits	<ul style="list-style-type: none"> Strategies to enhance person-centred and consumer-directed care need to be informed by people with dementia and their carers. This will support alignment of strategies with consumer needs. People with dementia and their carers have greater involvement in policy development and considering their own care and support.
Risks	<ul style="list-style-type: none"> Expectations need to be managed during consultations as resources are not unlimited and there may be disparate views.
Funding	<ul style="list-style-type: none"> To be funded out of existing DSS budget allocations.
Feasibility	<ul style="list-style-type: none"> This could be implemented in the short term.

Analyse, consolidate and align current dementia initiatives

A commonly held view of participants was that some of the programs and initiatives that are available to support people with dementia in the home care or residential care settings, carers or service providers, such as DBMAS and DTSCs, were very effective. However, these programs and initiatives are not necessarily available to everyone, particularly in regional and rural communities, and there were differing levels of awareness of these programs and initiatives. Participants expressed similar views on the available training and education opportunities.

The consensus from participants was to analyse the range of existing Commonwealth funded programs and training with the view to consolidating and improving the alignment of those that are most effective and consider strategies to make them more widely available. This review could also identify gaps in support to inform future policy initiatives.

Strategy	B. Analyse, consolidate and align the current dementia initiatives
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 1, 2, 3 and 4.
Description	Assess the capacity, capability and value of current Commonwealth funded dementia programs by analysing all existing Commonwealth funded dementia programs. Outcomes of the analysis would determine which initiatives should be consolidated, expanded and discontinued.
Benefits	<ul style="list-style-type: none"> More efficient, effective and coordinated services with possibilities for consolidation. A consolidation of current services may leverage their impact by making it easier for people to navigate and identify what is available. A consolidation of current services and discontinuing ineffective initiatives is also likely to create efficiencies that provide opportunities for expansion of existing effective services, such as broadening the reach to rural and remote areas, or piloting new initiatives and training and education programs.
Risks	<ul style="list-style-type: none"> Effective review of all existing programs is likely to take between 6 to 12 months. Implementation of any findings would be subject to Government agreement and funding availability.
Funding	<ul style="list-style-type: none"> Analysis to be funded out of existing DSS budget allocations.
Feasibility	<ul style="list-style-type: none"> This is an option for the short to medium term.

Specialised support

There was broad consensus from participants on the need to improve access to specialised support services. A variety of options received broad support, such as an increase in the roles of DBMAS and DTSCs; piloting the use of 'Flying Squads'; the use of specialist units for people with severe BPSD; and making existing transition support services more accessible for people with dementia.

Strategy	C. Increase the role, cohesiveness and coordination of DBMAS and/or DTSCs
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 1, 2, 3 and 4.
Description	<p>Participants identified a need to improve the level of specialist support for people with severe BPSD, both at an individualised and organisation-wide level. DBMAS was identified as well placed to deliver improved support at an individual level, while DTSCs were identified as being well positioned to provide education and knowledge about managing people with severe BPSD at the service provider level. Option B could be used to validate both propositions.</p> <p>There is scope to increase the alignment, cohesiveness, and coordination of both DBMAS and DTSC, which could be explored as part of Option B.</p> <p>Participants also thought DBMAS was well placed to assist with identifying and addressing behaviours triggered by unmet need.</p> <p>Both DBMAS and DTSCs would require increased resources to meet the expanded role.</p>
Benefits	<ul style="list-style-type: none"> Greater levels of assistance for service providers in providing care for individuals with severe BPSD. Assistance with improving organisation-wide capabilities in providing care for people with severe BPSD. Greater overall levels of care for people with severe BPSD.
Risks	<ul style="list-style-type: none"> Poor communication or cooperation between DBMAS and DTSCs may adversely affect coordination and service provision.
Funding	<ul style="list-style-type: none"> This model could be piloted using funding that was previously identified as being for the Dementia and Severe Behaviours Supplement.
Feasibility	<ul style="list-style-type: none"> This is an option for the short to medium term.

Strategy	D. Pilot the use of 'flying squads'
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 1, 2 3 and 4.
Description	<p>The use of flying squads—the models of which varied between geriatrician and nurse practitioner led but involved specialist assessment and multidisciplinary input—to provide support to residential care providers or carers of people with severe BPSD could be piloted to assess their effectiveness.</p> <p>A pilot could involve flying squads in three different geographic locations, a metropolitan; regional; and rural location.</p>

Strategy	D. Pilot the use of 'flying squads'
Benefits	<ul style="list-style-type: none"> It was thought that these flying squads would be cost effective in that they would bring care to the person with severe BPSD, resulting in earlier intervention a with the result of minimising even more resource intensive downstream interventions such as emergency department presentations. A pilot would be able to evaluate this.
Risks	<ul style="list-style-type: none"> Concerns regarding the number of flying squads required to service the whole country. May be difficult for the flying squad model to sustain long-term change and service improvement outcomes in the residential care facilities.
Funding	<ul style="list-style-type: none"> A budget to pilot and evaluate flying squads could be created from the funds that were previously allocated for the Dementia and Severe Behaviours Supplement.
Feasibility	<ul style="list-style-type: none"> Further work is required to develop the flying squad model and to clarify how flying squads would differ from, complement, or build on DBMAS, particularly in states where DBMAS is less established. This is an option for the medium term.

Strategy	E. Use of specialised units
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 2 and 4
Description	<p>The use of specialist units within general residential aged care facilities for those with severe BPSD is considered to be highly effective in the areas that these services are available. The units could be characterised by a specialised workforce, good dementia design and low levels of medical and physical restraint. While there are some units in existence, a lack of specialised support was identified as a significant problem by most forum participants. Increasing the availability of specialised units would provide support for people with severe BPSD.</p> <p>Participants thought that the description of these units should not add to the stigma around dementia and severe BPSD. Instead of names such as 'high care units' and 'high dependency units', names such as 'special care units' or 'special dementia units' should be used to emphasise a quality of life enhancing approach for people needing these specialised units. While the exact number of units required in each state/territory is not known, two to three additional specialised units per state/territory would substantially increase the availability of this type of care.</p>
Benefits	<ul style="list-style-type: none"> An expansion of specialist services would provide greater equity of access to these services throughout Australia. An opportunity to provide care which we know works for people with

Strategy	E. Use of specialised units
	BPSD. <ul style="list-style-type: none"> Improved service outcomes for people with severe BPSD.
Risks	<ul style="list-style-type: none"> Attracting a sustainable workforce for this model may be difficult. Therefore attention would need to be given to workforce development. Consideration needs to be given as to how the units will complement and not duplicate existing state-based psychogeriatric services.
Funding	<ul style="list-style-type: none"> Funding for specialised units could be allocated by DSS by designating priority places under the ACAR process. Under this option, existing providers could have existing places re-classified. Funds previously allocated to the Dementia and Severe Behaviours Supplement could be reallocated to a grants system where providers with severe BPSD places could apply for top-up funding.
Feasibility	<ul style="list-style-type: none"> This is an option for the medium term to long term.

Strategy	F. Increase access to rehabilitation and transitional accommodation for people with dementia
Forum objectives	<ul style="list-style-type: none"> Satisfies forum objectives 2 and 4.
Description	<p>Offer people with dementia access to cognitive rehabilitation to assist their independence and functioning in the community and residential care.</p> <p>The Australian Government funded Transitional Care Programme (TCP) is primarily focused on physical rehabilitation but has not been readily available for dementia care. It was proposed that transitional care models may have applicability in dementia care. The focus of these transition care models would be on re-enablement and minimising functional decline of the person with dementia.</p> <p>To enable greater access, criteria around entry into transitional accommodation could be modified to ensure there is a focus on people with dementia. In addition, providers need to engage DBMAS and DTSCs to improve the workforce capability of transition care.</p>
Benefits	<ul style="list-style-type: none"> Greater access to rehabilitation and transitional accommodation could address the need for early intervention, on a more individual basis. Access to transitional accommodation would allow both carers and people with dementia to acclimatise to a different environment so that the transition to residential care does not exacerbate an individual's symptoms on admission to residential care.
Risks	<ul style="list-style-type: none"> For some providers of TCP, this will require a substantial change to existing services and require a change to current staffing models to

Strategy	F. Increase access to rehabilitation and transitional accommodation for people with dementia
	provide a greater focus on dementia care.
Funding	<ul style="list-style-type: none"> • This strategy would require an amendment to the criteria around access to TCP and is not necessarily dependent on an increase in funding. • TCP providers may require support to develop appropriate service delivery models and to build their workforce capability.
Feasibility	<ul style="list-style-type: none"> • This is an option for the medium term.

Quality of life indicators

The establishment of aged care quality indicators focusing on the individual with dementia, including those with severe BPSD, was widely supported by participants.

Strategy	G. Introduction of aged care quality of life indicators
Forum objectives	<ul style="list-style-type: none"> • Satisfies forum objectives 1 and 3.
Description	<p>The introduction of indicators that cover both quality of care and quality of life would assist consumers in making decisions about their choice of aged care service providers, and also assist service providers in their continuous improvement of service delivery. Quality indicators would complement the current quality framework.</p> <p>The quality indicators should support the rights of residents covered in User Rights Principles 2014 Schedule 1—Charter of care recipients’ rights and responsibilities—residential care, and also consider the following ten dignity of care principles:</p> <ol style="list-style-type: none"> 1. Zero tolerance of all forms of abuse. 2. Support people with the same respect you would want for yourself or a member of your family. 3. Treat each person as an individual by offering a personalised service. 4. Enable people to maintain the maximum possible level of independence, choice and control. 5. Listen and support people to express their needs and wants. 6. Respect people’s privacy. 7. Ensure people feel able to complain without fear of retribution. 8. Engage with family members and carers as care partners. 9. Assist people to maintain confidence and a positive self-esteem. 10. Act to alleviate people’s loneliness and isolation.

Strategy	G. Introduction of aged care quality of life indicators
Benefits	<ul style="list-style-type: none"> • Builds on the Government’s existing quality indicator work. • Increase the transparency of care outcomes for consumers in making decisions about which services to access. • Inclusion of consumer input. • Help drive change and focus strategies on areas of need both for the individual and within organisations. • Provide solid data to inform policy around aged care in general, and dementia and severe BPSD specifically, at the government level. • Performance measurement, benchmarking and publication of performance data is likely to lead to improved service provision.
Risks	<ul style="list-style-type: none"> • Increased risk of administrative burden. • People with more severe BPSD or comorbidities may negatively skew results. • Measurement tools must reliably measure the quality indicators. • Quality Indicators and resident surveys must not be confused with compliance measurements.
Funding	<ul style="list-style-type: none"> • To be funded out of existing DSS budget allocations.
Feasibility	<ul style="list-style-type: none"> • Considerable work will be required to introduce aged quality of life indicators. The design of appropriate indicators; selecting the right measurement tool or developing a new tool are complex tasks to ensure the above risks are mitigated. • This is an option for the medium term.

Grants to pilot and evaluate new service delivery models

Strategy	H. Using funding grants to pilot and evaluate new service delivery models or initiatives
Forum objectives	<ul style="list-style-type: none"> • Satisfies forum objectives 1, 2, 3 and 4.
Description	<p>Using funding grants to pilot and evaluate new service delivery models or initiatives was proposed as a replacement for the Dementia and Severe Behaviours Supplement. It was proposed that these grants would be specifically targeted to address severe BPSD. Service providers would apply for grants to pilot innovative models and, if successful, could be distributed more broadly across the sector.</p> <p>Possible new service delivery models or initiatives that were proposed by participants include:</p> <ul style="list-style-type: none"> • respite care funding following the care recipient rather than being allocated to providers; • an expansion of the role of nurse practitioners;

Strategy	H. Using funding grants to pilot and evaluate new service delivery models or initiatives
	<ul style="list-style-type: none"> • increasing the leadership capability of the aged care workforce; • a better allocation of staff caseloads; and • improved knowledge translation of dementia research.
Benefits	<ul style="list-style-type: none"> • Development of innovative approaches to providing services for people with severe BPSD. • Successful innovations could be rolled out across the sector, improving service provision sector-wide.
Risks	<ul style="list-style-type: none"> • Duplication of trials and research that has already been undertaken.
Funding	<ul style="list-style-type: none"> • A grants program could be created from the funds that were previously allocated for the Dementia and Severe Behaviours Supplement.
Feasibility	<ul style="list-style-type: none"> • While clear funding criteria would need to be established, a grants program could be implemented relatively quickly, making this a short to medium term option.

5. Next steps

As noted in Section 4, the Australian Government requested that the forum provide policy options within the existing funding envelope. Some policy options received broader support from forum participants than other potential options.

The first policy option that Government should consider is to increase the current levels of engagement with people with dementia when determining future policy directions. Consultation processes would be greatly improved by increasing the role of people with dementia and their carers. Greater representation at the annual Ministerial Dementia Forum would be an effective way to ensure that the people who are most affected by policy changes are involved. However, greater consumer engagement and participation should not begin and end there, as these concepts should be kept in mind with the pursuit of any of the reform options presented in Section 4.

One of which is undertaking a review encompassing current dementia initiatives and education and training opportunities. In light of the feedback from forum participants, it would appear that it is now an appropriate time for DSS to begin to take stock of the current supports that are provided for people with dementia. The outcomes of the review will position DSS to support the findings of the forum and suggestions from participants with evidence of what works well and is supported by evidence, what needs to be expanded and what can be discontinued. It will also identify potential gaps and assist with prioritising options listed in Section 4, particularly under the headings of specialised support.

Two other initiatives that received broad support from participants, the introduction of quality indicators and improved transition care, both of which could be funded through the relevant DSS programs. Both proposals will require some planning but both could be implemented in the medium term.

Whilst broader funding considerations were beyond the scope of the forum, it was clear that efforts to ensure CDC is implemented throughout the whole aged care system, in both home care and residential care, and ensuring that funding is allocated to the consumer throughout their journey in the system, should be part of future funding policy considerations. Participants also made clear a desire for the current funding arrangements to be reviewed, particularly the existing ACFI funding arrangements. However, this was also beyond the scope of the forum and outside of the funding envelope.

Given that the overarching aim of the forum was to establish what is needed to improve the provision of dementia care both in residential aged care and home care including respite care, whilst remaining within the current funding envelope, it may not be possible to implement every option proposed in Section 4. Those options not able to be adopted at this time could be considered as potential options for the next wave of reforms to the aged care system. Similarly, the views of many participants that the broader funding system should be reviewed and that funding should follow the consumer rather than the provider, could also be considered in the context of future reforms to the aged care system.

Appendix 1: List of Ministerial Dementia Forum participant organisations

Organisation
ACH Group Inc
Aged and Community Services Australia
Aged Care Financing Authority
Alzheimer's Australia
ANZSGM
Applied Aged Care Solutions Pty Ltd
Arcare Qld
Australian Nursing & Midwifery Federation
Australian Unity
Bethanie
Bill Crawford Lodge
Blue Care
Braeside Hospital
BUPA Care Services Australia
Canberra Hospital
Carer, Alzheimer's Australia
Carers Australia
Catholic Health Australia
Catholic Homes
Caulfield Hospital
Consumer
COTA
DBMAS Qld
Department of Health
Department of Social Services
ElderCare
Former carer
formerly Australian Institute for Primary Care
Group Homes
Hall & Prior, NSW Regional Office
Hall & Prior, WA
HammondCare
University of Newcastle
Helping Hand SA
Jewish Care Victoria
Kincare
Synovum Care Group

Organisation
LASA
Metro South Health
Minister Andrew's Office
NARI
National Aged Care Alliance
NHMRC
NSW Dementia Collaborative Research Centre
NSW/ACT DTSC
Opal Aged Care
RDNS
RSL Care
Rural Northwest Health
Salvation Army, Southern Territory
Shepparton Villages
Silver Chain
St Vincent's Health Australia
The Queen Elizabeth Hospital
UnitingCare Australia
Vic/Tas DTSC
VincentCare Victoria
Whiddon Group
Wintringham VIC

Appendix 2: Ministerial Dementia Forum – 11 September 2014 Agenda

Ministerial Dementia Forum
‘Dementia care – core business for aged care’
Oaks-on-Market Melbourne
60 Market Street, Melbourne

09.30 – 10:00am	Registration / continuous Tea and Coffee from arrival	
10.00 – 10.05am	Opening Remarks	Ms Liz Forsyth
10:05 – 10:20am	Introduction and setting the scene	Dr Sue Koch
10:20 – 10:45am	The Hon Minister Mitch Fifield	
10:45 – 10:55am	Service provider	Dr Stephen Judd
10:55 – 11:05am	Clinician	Professor Henry Brodaty
11:05 – 11:15am	Consumer	Ms Kate Swaffer
11:15 – 11:20am	Getting started	Ms Liz Forsyth
11:20 – 12:10pm	Group session 1	Ms Liz Forsyth/Table Captains
12:10 – 12:30pm	Feedback from Group session 1	Ms Liz Forsyth
12:30 – 13:00pm	LUNCH	
13:00 – 2:00pm	Group session 2	Ms Liz Forsyth/Table Captains
2:00 – 2:20pm	Feedback from Group session 2	Ms Liz Forsyth
2.20 – 3.20pm	Working Afternoon Tea - Group session 3	Ms Liz Forsyth/Table Captains
3.20 – 3.40pm	Feedback from Group session 3	Ms Liz Forsyth
3.40 – 4.15pm	Plenary Session - Clarifying/refining recommendations	Ms Liz Forsyth
4:15 – 4.30pm	Chair – Co-Chair to close the Forum	Ms Sue Pieters-Hawke

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