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The findings in this report are based on a qualitative study and the reported results reflect a perception of participants who attended the Ministerial Dementia Forum on 8 December 2016 but only to the extent of the sample surveyed, being the Department approved representative sample of people living with dementia, carers, service providers, clinicians, and the Australian Government. Any projection to wider personnel and/or stakeholders is subject to the level of bias in the method of sample selection.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, service providers, clinicians, carers, people living with dementia and Australian Government stakeholders consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

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Executive summary

Dementia is the gradual, progressive and irreversible decline in brain function. It is an umbrella term describing a syndrome, meaning it is characterised by multiple symptoms which may include difficulties with language, memory, perception, changes in personality and reduced cognitive skills.\(^1\) With Australia’s ageing population, it is important that the Australian Government provides appropriate levels of support for people living with dementia, their carers and family, and aged care service providers to ensure that people living with dementia receive high quality care.

In 2014, the Australian Government announced its intention to consult widely with key dementia stakeholders, experts and consumers on how to improve care for people living with dementia. Consistent with this intention, the inaugural Ministerial Dementia Forum ‘Dementia Care – Core Business for Aged Care’;\(^2\) was held on 11 September 2014 in Melbourne and a second forum, ‘Dementia Care – Core Business’, held the following year on 6 November 2015.\(^3\)

As part of the outcomes from the first two Ministerial Dementia Forums, the Government announced it would be redesigning existing dementia support programs to ensure improved consistency and reach to rural and remote areas. Phase one of the redesign focused on transitioning the Dementia Behaviour Management Advisory Service (DBMAS) to a single national program and streamlining the Dementia Training Study Centres (DTSC) and Dementia Care Essentials Program into a single national Dementia Training Program (DTP).

In January 2016, the Australian Government announced it would work with stakeholders to undertake phase two of the redesign, focusing on improving the current suite of dementia consumer support programs funded by the Australian Government. The programs in the scope for redesign are the National Dementia Support Program and Service Delivery Pathways Program, which are both delivered by Alzheimer’s Australia. The aim of the redesigned programs is to facilitate appropriate supports for people living with dementia and their carers across the lifecycle of the disease.

The third Ministerial Dementia Forum, ‘Redesigning Dementia Consumer Supports’ was held on 8 December 2016 with 61 participants from across Australia representing people living with dementia, carers, service providers, clinicians, and the Australian Government.

The purpose of the 2016 Ministerial Dementia Forum was to consider the redesign of dementia consumer supports and seek feedback from participants to:

- examine the consumer journey with dementia;
- discuss how Commonwealth-funded dementia consumer support programs could be structured in order to achieve the aims above, in the context of the current funding envelope;
- explore how existing or emerging policies in the broader aged care, health, and social support sectors can be leveraged to improve the consumer journey with dementia; and
- consider approaches that could increase the reach and sustainability of dementia consumer support programs.

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


During the Forum, participants discussed the following questions:

1. What should be the scope of the redesigned suite of dementia consumer support programs?

2. What can be done in the short-term, medium-term and long-term to assist consumers to navigate the interfaces between the health and aged care systems, particularly when transitioning between care settings?

3. When are the key touch points for a dementia consumer support program and which supports have the greatest long-term impact?

This report outlines the feedback provided on the day and highlights issues strongly supported by some or all Forum participants. It should be noted that some ideas expressed by Forum participants may be outside the scope of the Dementia Consumer Supports program redesign but are still a useful guide to Government on the priorities identified by key stakeholders. The main themes that emerged from each discussion shared many common and interrelated elements. These themes are as follows:

**Dementia friendly communities and reducing stigma**

Forum participants:

- reported that more can be done to strengthen the approach/implementation of making our communities dementia friendly to reduce stigma and increase awareness; and

- stressed the need to improve dementia literacy across the system.

**Early contacts with primary health and earlier diagnosis**

- Forum participants emphasised the need to increase the importance placed on early interventions and diagnosis, particularly in the primary health space (GPs, nurses, allied health). These health professionals should be able to provide good information and guidance.

**Navigating the system**

- Forum participants stressed how critical it is to be able to navigate the system. There is a wide range of supports and information available to people living with dementia, however people are often unaware of or do not know how to access these services. People should have access to resources to assist them with this when necessary.

- It was recognised that there is significant value in tailored tools and resources (updated and audited by consumers) to guide the myriad of professionals involved.

**Transitions and understanding the journey**

Forum participants:

- were of the view that transition should be redefined, taking it from the perspective of the consumer and their support network. Doing so, will help people understand the journey that will unfold for them in a respectful and timely way through these transitions;

- recognised that efforts should not just focus on improving the early stages but that the latter stages, including the end-of-life are also important; and

- stated that a more focused approach on individuals is required, one that recognises that their circumstances need to be accounted for on an individual basis. Support services need to be able to flex around the context, setting, and environment.
Support for carers

Forum participants:

- were of the view that it is crucial that carers are also supported in their role. Strengthening the support for carers should be a focus; and
- stated that access to tailored respite and day care play an important role in supporting individuals living with dementia and carers.

The right system to meet the diversity of consumers

Forum participants:

- emphasised the need to put the redesigned suite of dementia consumer support programs through a lens that addresses issues to do with geography, disadvantage, and the diversity of cohorts of individuals;
- identified the need to determine whether the system is fit for purpose for the range and diversity of consumers, thinking of individual needs in a more holistic way (e.g. multiple aspects of diversity and managing those considerations across all transitions); and
- stressed the role of the workforce and how they can be up-skilled (and appropriately paid) needs to be considered in the context of the changing requirements for individuals.

Health/aged care interface

Forum participants:

- reported that it is vital to improve the health/aged care interface. Opportunities exist in the policy and teaching context to bring aged care into the ecosystem. In particular, there is an opportunity to improve the interface between the acute care, primary care and aged care sectors by increasing the collaboration between Local Hospital Networks (acute care), Primary Health Networks (primary care), and aged care. This would make the various transitions of dementia easier for consumers; and
- stated the importance for the redesigned suite of programs to think about the person’s needs in totality rather than the emphasis on dementia. This includes their broader health needs.

Role of technology

Forum participants:

- thought that the role of technology needs to be further explored, including opportunities for “My Health Record”; and
- identified technology as a key enabler to improving the supports available to carers.

Financial contribution to supports

- There were not consistent views amongst forum participants regarding the issue of financial contributions by individuals. However, forum participants were of the view that the pricing signals going to market not preclude people from accessing services when needed.
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclaimer</td>
<td>ii</td>
</tr>
<tr>
<td>Executive summary</td>
<td>iii</td>
</tr>
<tr>
<td>1 Background</td>
<td>1</td>
</tr>
<tr>
<td>2 Approach</td>
<td>3</td>
</tr>
<tr>
<td>3 Forum outcomes</td>
<td>4</td>
</tr>
<tr>
<td>3.1 Group Session One</td>
<td>4</td>
</tr>
<tr>
<td>3.2 Group Session Two</td>
<td>8</td>
</tr>
<tr>
<td>3.3 Group Session Three</td>
<td>12</td>
</tr>
<tr>
<td>3.4 Written submissions</td>
<td>14</td>
</tr>
</tbody>
</table>
1 Background

Dementia is the gradual, progressive and irreversible decline in brain function. It is an umbrella term describing a syndrome, meaning it is characterised by multiple symptoms which may include difficulties with language, memory, perception, changes in personality and reduced cognitive skills.\(^4\)

In 2014, the Australian Government announced its intention to consult widely with key dementia stakeholders, experts and consumers on how to improve care to people living with dementia. Consistent with this intention, the inaugural Ministerial Dementia Forum, ‘Dementia Care – Core Business for Aged Care’, was held on 11 September 2014.\(^5\) The aim of Forum was to gain feedback from key stakeholders and experts 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. Forum participants made a range of recommendations to Government that were based on the discussions on the day. Recommendations included the need to conduct an analysis of Australian Government-funded dementia support programs to examine their effectiveness, coordination and alignment.

In 2015, KPMG was commissioned to conduct the Analysis of Dementia Programs.\(^6\) A second Ministerial Dementia Forum, ‘Dementia Care – Core Business’,\(^7\) that was held on 6 November 2015 drew on the analysis of this review to consider how to ensure dementia consumers can navigate the health and aged care system, as well as what objectives and outcomes dementia support programmes should have.

On the basis of the review’s findings and the feedback from participants of the second Ministerial Dementia Forum, the Government announced it would be redesigning existing dementia support programs to ensure improved consistency and reach to rural and remote areas.

Phase one of the redesign focused on the following sector support programs:

- The Dementia Behaviour Management Advisory Service (DBMAS) transitioned to a single national program, rather than being provided by eight separate state and territory-based organisations.
- The Dementia Training Study Centres (DTSC) and Dementia Care Essentials Program were streamlined into a single national Dementia Training Program (DTP).

In January 2016, the Australian Government announced it would work with stakeholders to undertake phase two of the redesign, focusing on improving the current suite of dementia consumer support programs funded by the Australian Government. The programs in the scope for redesign are the National Dementia Support Program and Service Delivery Pathways Program, which are both delivered by Alzheimer’s Australia. The aim of the redesigned programs is to facilitate appropriate supports for people living with dementia and their carers across the lifecycle of the disease.

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\(^4\) Australian Institute of Health and Welfare (AIHW) 2012, Dementia in Australia, catalogue no. AGE 70, AIHW, Canberra.


The purpose of the 2016 Ministerial Dementia Forum was to consider the redesign of dementia consumer support programs and seek feedback from participants to:

- examine the consumer journey with dementia;
- discuss how Commonwealth-funded dementia consumer support programs could be structured in order to achieve the aims above, in the context of the current funding envelope;
- explore how existing or emerging policies in the broader aged care, health, and social support sectors can be leveraged to improve the consumer journey with dementia; and
- consider approaches that could increase the reach and sustainability of dementia consumer support programs.
2 Approach

The third Ministerial Dementia Forum, ‘Redesigning Dementia Consumer Supports’ was held on 8 December 2016 with 61 participants from across Australia including people living with dementia, carers, researchers, clinicians and representatives from peak bodies, service providers, and the Australian Government. The forum was Co-Chaired by Associate Professor Susan Koch and Ms Sue Pieters-Hawke and the Hon Ken Wyatt AM, MP gave a short address to open the Forum. Liz Forsyth, Global Lead: Human and Social Services and Deputy Chair, KPMG Australia, facilitated the Forum.

The Forum consisted of three workshop sessions, involving round table discussions amongst the table groups. Each table was led by a table captain, who guided the discussion to ensure that each participant had an opportunity to contribute to the table discussion. Each table also had a table scribe (nominated amongst table participants) to capture the key ideas within the discussions.

At the end of each workshop session, table captains (or delegated to another table member) presented their table’s three key issues to the broader group. Following the conclusion of the third workshop session, the table captains met with the facilitator to reach a broad consensus on a high-level summary of the key themes from each workshop session. These themes were then presented back to the broader group to test and verify these findings with Forum participants.

The three workshop sessions discussed the following key questions respectively:

1. What should be the scope of the redesigned suite of dementia consumer support programs?
2. What can be done in the short-term, medium-term and long-term to assist consumers to navigate the interfaces between the health and aged care systems, particularly when transitioning between care settings?
3. When are the key touch points for a dementia consumer support program and which supports have the greatest long-term impact?

Following the conclusion of the Forum, scribes’ reports were developed based on the table notes made by scribes and sent to table captains for verification. The National Aged Care Alliance, the Aged Care Sector Committee, and consumers (who were either present or unable to attend on the day) were also provided with an opportunity to provide feedback through written submissions. Six written submissions were received. These notes and submissions, along with the summary findings recorded on the day, have been analysed to identify key themes. This analysis has formed the basis of this report.

The intention of this report is to provide an accurate record of the Forum’s discussions and provide the Government with clear directions to consider as it continues its work in redesigning dementia consumer supports.

Section 3 presents the Forum’s outcomes across the three workshop sessions.
3 Forum outcomes

The following section describes key and additional themes that emerged from the group discussion during each of the three Group Sessions.

3.1 Group Session One

3.1.1 Question

**What should be the scope of the redesigned suite of dementia consumer support programs?**

To assist with the discussion, the following sub-questions were provided:

- What level of effort should be allocated to consumer supports in the pre-dementia stages, noting resources will be limited?
- What role should the redesigned consumer support program have in service capacity building versus delivery of information and services to consumers?
- How do we best meet the needs of consumers in a constrained funding environment? Should services be prioritised to a particular stage of the dementia journey (e.g. post-diagnostic supports) or triaged to those who face additional barriers (e.g. people from diverse backgrounds or people who live alone)?
- How realistic is a goal of national consistency across Australia? Are there certain service elements which are better delivered by community/local organisations rather than at the national level?

3.1.2 Key themes

The key themes that emerged from Group Session One on what should be the scope of the redesigned suite of dementia consumer support programs are:

**Integrated settings**

*Forum participants stated the importance for the redesigned suite of programs to think about the person’s needs in totality rather than the emphasis on dementia. This includes their broader health needs:*

- A person’s needs should be considered in totality rather than simply emphasising their dementia. Resources could be combined across disease types in order to effectively meet consumers’ healthcare needs, for example, between Diabetes Australia and Alzheimer’s Australia.
- Risk factors that lead to chronic disease should be identified in people living with dementia, with joint funding provided to administer risk reduction programs. Many generic health factors influence a wide range of health conditions including dementia so more needs to be done to better integrate funding across health programs and services.
Dementia friendly communities and reducing stigma

Forum participants reported that more can be done to strengthen the approach/implementation of making our communities’ dementia friendly to reduce stigma and increase awareness:

- Despite recent efforts and past campaigns to increase dementia awareness throughout the community, many people still expect people living with dementia to be “in their pyjamas” and deny that it is possible for well-functioning people living with dementia to have the disease. The continued lack of awareness is driving the stigma attached to living with dementia. In order to build dementia friendly communities, further community education is needed to reduce this stigma.

- Given the role carers and families can play in identifying dementia, there is significant value in continuing to educate the general population to assist with earlier diagnosis.

- Some forum participants reported examples where this stigma extends to health professionals. For example, general practitioners (GPs) are well placed to observe changes in people over time and often notice these changes. However, due to the stigma associated with dementia, they do not always ask the right questions to help make an early diagnosis.

- A strategy to build public awareness that emphasises positive messages (i.e. ‘life continues’) and promotes prevention and risk reduction should be developed. The strategy should take the form of a pervasive mass media campaign, which can draw on successful past campaigns. The strategy could also include audience-specific messages that are tailored to different groups (e.g. children, culturally and linguistically diverse communities, etc.). The campaign should provide a clear, consistent message with key resources free, centralised, and accessible.

Early contacts with primary health and earlier diagnosis

Forum participants emphasised the need to increase the importance placed on early interventions and diagnosis, particularly in the primary health space (GPs, nurses, allied health). These health professionals should be able to provide good information and guidance:

- While the benefits of receiving an early diagnosis are well documented, getting an actual diagnosis can be very difficult. It is common for most people to experience difficulty finding out what is wrong and how to seek help due to a lack of knowledge on the part of general practitioners (GPs). People also often have multiple interactions with the health system prior to receiving a diagnosis due to in part to a lack of insight on behalf of both the individual and their GP.

General Practitioner education:

- GPs often lack the knowledge to deliver appropriate pre-diagnostic support, particularly in rural areas. A GP training scheme would assist GPs to improve patient care and ensure people are being diagnosed as soon as possible. Dementia specific education could also be provided to nurses to ensure that they are able to recognise key symptoms and know how to ask the right questions of patients.

- GP education should focus awareness on the broad spectrum of how dementia may present and where they should advise patients go for help. Resources to assist with this are already out there (e.g. clinical practice guidelines) but they need to be nationally distributed to health professionals.

- GP education should emphasise dementia prevention strategies (e.g. ‘Your Brain Matters’), as well as prevention strategies for other diseases (e.g. improving cardiac health by reducing smoking rates), to promote the understanding that people living with dementia can also live a healthy life.

- Education programs for health professionals and community awareness campaigns for the general public should be linked to emphasise and assist with an increase in earlier diagnosis.
These programs and campaigns should include consistent messages that aim to de-stigmatise providing services to people living with dementia.

**Primary Care and support:**

- Primary care should provide a model of support that includes access to necessary resources and links to qualified dementia specialists. This will require dementia to be recognised as a chronic disease and mental health disorder, allowing people access to the Medicare Benefits Scheme (MBS). As dementia is not classified as a mental health disorder under the Better Access to Mental Health Scheme, MBS items cannot be charged. Carer support could then also be provided through the MBS.

- People should be given a ‘right’ to a care plan at the point of diagnosis to ensure they are receiving appropriate post-diagnosis support. People will seek a diagnosis if they know there are supports available.

- The type of support required post-diagnosis will change over time. For example, during early post-diagnosis, people may require support to stay in employment and continue to lead their lives normally.

- Early intervention should be a future funding priority.

**Navigating the system**

Forum participants stressed how critical it is to be able to navigate the system. There is a wide range of supports and information available to people living with dementia, however people are often unaware of or do not know how to access these services. People should have access to resources to assist them with this when necessary:

- There is significant value in tailored tools and resources (updated and audited by consumers) to guide the myriad of professionals involved.

- Navigating the complex system while having a cognitive impairment is very challenging and consumers find it difficult to determine where to go after receiving a diagnosis. While there is a lot of information, what is missing is the ability for people to access it in a clear and coherent way. Therefore, the available information needs to be collated and easily accessible. A case manager (navigator) can help people through the system. People may need a navigator at different points in their journey so the challenge is to ensure that people living with dementia have access to this kind of support. Public awareness of navigation services is also critical.

- While there is opportunity for technology in this space (for example, the Massive Open Online Course (MOOC) ‘Understanding Dementia’ run by University of Tasmania and through social media) sometimes people need to speak to another person. Additionally, putting all resources on-line may prevent some people from accessing that support due to poor computer literacy.

- The National Dementia Helpline is well-regarded but its capacity should match demand, including potentially expanding operational hours. The Translating and Interpreting Service is crucial to ensure equity of access to the National Dementia Helpline for non-English speakers.

- The key worker model is considered the gold standard approach for supporting people at critical touch points. While most consumers would prefer their own key worker, funding from home care packages could be used to support this navigation function if essential.

- Some participants expressed frustration with the aged care eligibility requirements as it is unclear why a person’s age determines their access to support rather than their care needs, consistent with other chronic diseases. Such restrictions make navigating the system very difficult for consumers, given the criteria can vary depending on people’s individual circumstances.
• Participants observed that it can be particularly difficult to navigate services when a person with dementia approaches the palliation stage of their journey.

• Some participants observed that people living with dementia may need additional support to navigate the changes to the aged care sector that are occurring as a result of the shift to Consumer Directed Care (CDC).

Support for carers

Forum participants were of the strong view that it is crucial that carers are also supported in their role:

• Carers require both knowledge and support to be successful. There is a need for more wide ranging education for carers that is tailored to their individual situation. Support programs should support carers at key touch points when the circumstances of their loved one changes, as well as catering for ongoing stress, burden and loss. Regular respite programs run by qualified nursing staff are an important component. Carers groups and mentoring are also considered highly useful supports.

• Participants expressed concern that the current policy settings unintentionally hinder carer support, potentially creating further stress on carers. Carers require a carer directed support program with tiered supports providing:
  • information about supports (from GPs, allied health professionals, etc.); and
  • improved availability of respite places and greater flexibility of the service and the skills of staff in all types of respite.

Diversity of consumers

Forum participants emphasised the need to put the redesigned suite of dementia consumer support programs through a lens that addresses issues to do with geography, disadvantage, and the diversity of cohorts of individuals:

• The diversity of consumers requires person-centred supports that can be tailored to individuals, rather than siloed groups. People often have multiple sources of diversity or disadvantage and require support tailored specifically to their circumstances.

• There is a need to recognise, capture and respond to the diversity of views among people living at different stages of dementia to inform service development.

• Where a group has unique needs, a specialised service may be appropriate. However such services may not be economically viable in a consumer-directed care environment. Consequently, the services they want and need may not be available and government may have to fill gaps.

Priorities in a constrained funding environment

Forum participants also observed that:

• It is evident that that there will be less money available per individual as the number of people living with dementia increases. Therefore, consideration should be given to what supports are most important given limited resources, with a focus on assessment and diagnosis and improving quality of life.

• CDC will continue to drive changes to existing services for all consumers, including those living with dementia. Some participants identified the risk that services some people living with dementia have relied on may no longer be available creating gaps in coverage.
• It is important for consumers to be able to stay at home as long as possible so facilitating this should be a high priority. This includes supporting people through key transition points in their journey (e.g. giving up driving).

• Continuity of funding for successful programs should be prioritised. For example, the “living with dementia” program is highly successful, however it has long waiting lists and there is no follow on education after it finishes.

• However, some participants challenged the premise of a constrained funding environment. Rather, they would prefer government design dementia consumer supports by considering what they would look like with unlimited funding and then pare back from this starting point.

3.2 Group Session Two

3.2.1 Question

What can be done, in the short-term, medium-term and long-term, to assist consumers to navigate the interfaces between the health and aged care systems, particularly when transitioning between care settings?

To assist with the discussion, the following sub-questions were provided:

• How might existing health system supports be leveraged to improve the consumer journey with dementia in a cost-effective way?

• What are the most difficult transitions for a person with dementia?

• Aside from having a dedicated care-coordinator, how could people living with dementia be supported to understand and access available services?

• What are the opportunities, including emerging technologies, to improve access to support for people in rural and remote areas?

• Are there particular consumers who are more at risk of struggling to navigate the systems? How can we help them?

3.2.2 Key themes

The key themes that emerged from Group Session Two on what can be done, in the short-term, medium-term and long-term, to assist consumers to navigate the interfaces between the health and aged care systems are:

The right system to meet the diversity of consumers

Forum participants identified the need to determine whether the system is fit for purpose for the range and diversity of consumers, thinking of individual needs in a more holistic way (e.g. multiple aspects of diversity and managing those considerations across all transitions):

• In order to create a system that works for current consumers, the profile of the population it is supposed to service needs to be determined.

• While it is important to consider whether the system works for at-risk or disadvantaged groups, it should not be assumed that it currently works for others.
Definition of ‘transition’

Forum participants were of the view that transition should be redefined, taking it from the perspective of the consumer and their support network:

- A ‘transition’ is not just from one physical entity to another (e.g. home to acute care), rather what can be defined as a transition depends on the individual and their emotional, physical and financial circumstances. Therefore, transitions should not just be considered as physical changes in the environment but also emotionally driven changes. For example, losing your driver’s licence may not be a significant transition for somebody who rarely drove, whereas for others it would represent the loss of their independence.

- Transitions can occur throughout the ‘journey’, starting with the first realisation that something is not quite right, to raising concerns with a GP or memory clinic, to receiving diagnosis, dealing with the stress of diagnosis, loss of friends and independence, etc. Transitions can also include various crisis points where the person and their carer interact with the health care system (e.g. one or both become ill), accessing respite services for the first time, entry into permanent residential aged care, and end-of-life care.

- Moving into residential aged care is widely recognised as a fundamentally difficult transition. There needs to be forward planning of this process by both individuals and care providers in order to ensure that the transition is as easy as possible for the consumer when they enter the facility and their other supports finish (e.g. home care packages and Alzheimer’s Australia resources). With forward planning, this transition can be done at the right time and pace for the individual consumer, with access to the supports they require (e.g. mentoring, financial support, etc.). Barriers to this transition include the funding service option, advocacy (knowing how to assess and decide on the right facility), and emotional/psychological adjustment.

- The transition to aged care is also hindered by the physical design of aged care facilities. While facilities reside in the community, they are often behind large walls, creating fear and reducing integration into the community. Operators should consider social design principals to make them more accessible to people.

- The transition to palliation and the transition that takes place during advance care planning were identified as being particularly difficult transition points where adequate support needs to be available.

- The transition from the community to hospital carries significant risk due to a lack of knowledge transfer between the two systems. In particular, personal (non-clinical) information may be lost. A solution may be to allow ‘My Health Record’ to record this information. Whatever solution is developed, it should be supported by a national standard for knowledge transfer.

Understanding the journey

Forum participants were of the view that transition should be redefined, taking it from the perspective of the consumer and their support network. Doing so, will help people understand the journey that will unfold for them in a respectful and timely way through these transitions:

- Planning for transitions often happens too late. At points where there is trauma, emotion or fear it can be hard to find information in the moment. Therefore, work needs to be done as soon as possible to plan for future transitions, anticipating what these points will be for each consumer. The focus of this should be on tailoring supports to the individual needs of consumers and allowing people to manage their journey themselves as appropriate. This model, where people receive the support they need at the relevant touch points, does not have to be a key worker model – for example, a shop front could be set up in the community so that consumers can talk to somebody face-to-face. This presence in the community would also serve to reduce stigma.
• Understanding the range of services available and then accessing those services could also be facilitated by:
  • nurse practitioners and GP nurses, who could receive additional training to enable them to play a key role in navigation and support;
  • peer support and facilitated community events for people living with dementia, carers and service providers;
  • consistent access/events that are locally driven; and
  • word of mouth.

Consumers' support networks

Forum participants emphasised the need to think about the specific relationship that consumers have with their support network and the implications of transition on the carer too. Consideration should be given to strengthening the support for carers, including mentoring:

• Dementia is a unique chronic disease due to the gradual decline in cognition. This places greater emphasis on the role of the carer and their relationship with the consumer. This ‘dyad’ of the person with dementia and their support network, plays a critical role. Receiving good care relies on having a carer to advocate on your behalf and communicate your diagnosis to the relevant services. For example, while dementia impacts your whole life, people without an advocate will struggle to fill out the Centrelink paperwork required to access other supports they need.

• Ensuring carers are supported too is critical to ensuring people living with dementia are supported. Tailored support for the carer should be available at all transition points. There are currently gaps where only limited support for carers is available (e.g. transition to residential aged care – carers report finding it difficult to assess which nursing home would be appropriate, etc.). Carer mentor programs are well-received, particularly by those who are caring for newly diagnosed consumers. However, later in the journey, other support such as tailored respite, becomes more important in supporting the dyad through transitions that are difficult for them.

• ‘At risk’ consumers and consumers who do not have an advocate are in a more difficult position when navigating the interfaces between the health and aged care systems. ‘At risk’ consumers include: young people accessing inappropriate services; older people with technology challenges; people with other disabilities; people living in regional/rural areas; Aboriginal and Torres Strait Islanders; culturally/linguistically diverse communities; people who are lesbian, gay, bisexual, trans, and/or intersex; people with low health literacy; and care leavers. Therefore, it is important that these vulnerable people are identified and provided with the support that they need to advocate for themselves.

Dementia literacy

Forum participants stressed the need to improve dementia literacy across the system:

Consistent with the observations made in Group Session One regarding the need for greater dementia public awareness and greater education for GPs and health professionals more broadly:

• Significant work is needed to improve dementia literacy across the system and amongst the general public. GP education would benefit from a broad GP information kit that identifies the steps of diagnosis and this should be distributed throughout Australia. This kit should be developed in collaboration with consumers to ensure it clearly sets out what consumers require at each stage to be properly supported by their GP. It is important that other allied health workers also receive professional training about dementia and people with cognitive impairment to ensure the standard
of care provided to these patients remains high. All training for health professionals should specifically provide information on the types of dementia.

- Following diagnosis, there needs to be a clear first step to accessing support (e.g. the helpline) that identifies the options available at that time. While there is a kit available through the helpline, if you do not know about the helpline you cannot access the kit. There is a gap in providing people in the early post-diagnosis stage with the information they need to access services. This is exacerbated by people not contacting agencies they feel do not represent them properly (e.g. Alzheimer’s Australia, Carers Australia, etc.). A mass media marketing campaign that aims to increase the number of people accessing the helpline could address the lack of awareness in the short-term.

- Research has found that people in the 30-40 year old age group do not want to hear messages about dementia, even though it is typically at this stage when dementia begins. Consideration should be given on how to engage best with this cohort.

- There is not a lot of information available on how to reduce the risk of other chronic disease in people living with dementia. Resources for other chronic diseases could be integrated with those for dementia to ensure that a person’s health is considered more comprehensively.

**Health/aged care interface**

*Forum participants reported that it is vital for us to improve the health/aged care interface. Opportunities exist in the policy and teaching context to bring aged care into the ecosystem:*

- Currently, the acute care, primary care and aged care sectors are siloed. While the Commonwealth Government has a policy agenda to drive collaboration between Local Hospital Networks (acute care) and Primary Health Networks (primary care), there is no agenda to link in aged care to this network. A tripartite model should be developed where there is significant collaboration between the three sectors in order to make transitions easier for consumers.

- Aged care is also siloed from the tertiary education sector. While there are ‘teaching hospitals’, there are no ‘teaching aged care facilities’. There should be a structured approach to teaching in the aged care sector that includes formal relationships between aged care providers and tertiary education institutions, rather than the current ad hoc approach.

- The siloed nature of the health and aged care sectors has resulted in a lack of access to appropriate medical care within aged care environments (both specialist care and GP care). While aged care should not be medicalised, medical care should be made more accessible in aged care settings. The development of community respiratory physicians in the UK is an example of international best-practice in this area.

- There is an opportunity to improve the partnerships between organisations/peak bodies representing people living with dementia and other disease groups that share common characteristics and risk factors.

**Role of workforce**

*Forum participants stressed that the role of the workforce and how they can be up-skilled (and appropriately paid) needs to be considered in the context of the changing requirements for individuals:*

- In order to appropriately support consumers through transitions, the current workforce requires sufficient training and support. Nursing, allied health and medical students should be exposed to aged care during their university courses. Certificate III and IV courses can be of very low quality and attract students that are not necessarily ideal for the type of work. Courses should focus more on dementia care specifically and current workers should be up-skilled with accredited training.
• Given the challenges attracting an appropriately skilled workforce to regional areas, specific capacity building initiatives should be provided to the existing workforce in order to up-skill local workers to support transitions.

• The diversity of both the workforce and the consumers should be considered in this context. Both groups will have different needs regarding workforce development and service delivery that need to be addressed. People in the workforce can also have multiple diversity characteristics that may create disadvantage for them and the system needs to understand how this relates to the goal of up-skilling the workforce and improving service delivery.

• Importantly, the workforce should be paid an appropriate wage for their level of training and experience that reflects the importance of their work.

Role of technology

Forum participants thought that the role of technology needs to be further explored, including opportunities for “My Health Record”.

• Emerging technology is not just important for people in rural and regional areas. We are at a tipping point where there are more people requiring care than there are unpaid carers available. Therefore, it needs to be determined how technology can be used to fill this gap. There is potential to implement international best-practice in this space.

• Emerging technology that allows people to have the best possible life and assists carers to continue to work should also be explored. For example, the emergence of assisted driving technologies could enable transport for people living with dementia that carers would typically provide. This will help to reduce the number of people leaving the workforce to take on carer roles. Over the coming decades, many people who would have taken on carer roles may not be able to leave the workforce for financial reasons – technology may provide an alternative to increased government support in such situations.

• An e-health record that integrates health and aged care information would support transitions that otherwise assume a person has no cognitive impairment. This would also help make hospitals more dementia friendly.

3.3 Group Session Three

3.3.1 Question

When are the key touch points for a dementia consumer support program and which supports have the greatest long-term impact?

To assist with the discussion, the following sub-questions were provided:

For consumers:

• Looking back on your own journey, what do you wish you had access to or had accessed at the beginning?

• Considering the current suite of available supports, which have you used, where in your journey have you used them and which did you find most valuable and why? Which would you be prepared to make a financial contribution to?

For professionals:

• Considering the current suite of available supports, which would you consider to have the greatest long-term impact, and why?
• Do you feel that there is equity for consumers in accessing services?
• Are there patterns you have observed about key cross roads/crisis points in the dementia journey? What early intervention supports might have delayed or prevented these?

3.3.2 Key themes

The key themes that emerged from Group Session Three on when are the key touch points for a dementia consumer support program and which supports have the greatest long-term impact are:

Touch points differ by individual

Forum participants stated that it is difficult to pick a single touch point – it is about a much more focused approach on individuals and recognising that their circumstances need to be accounted for on an individual basis. Support services need to be able to flex around that context, setting and environment:

• The key touch points differ depending on the individual but typically occur when there is some kind of transition. While there is no one-size fits all approach identifying when a person will need particular services, key touch points can include:
  • pre-diagnosis;
  • first contact with GP;
  • referral to a specialist who has specialist knowledge regarding cognitive impairment and dementia;
  • initial diagnosis and acceptance of that diagnosis;
  • being referred to and accessing appropriate services post-diagnosis for the first time
  • losing a driver’s licence
  • accessing day care and respite for the first time;
  • significant periods of change or crisis, including for carers; and
  • transitions to residential aged care and palliative care.
• However, how do professionals ensure access to the right sort of support, particularly post-diagnosis? A solution may be to develop a ‘call back’ service where individuals who contact the helpline are called back and provided with an individual solution to their needs.
• Specific consideration needs to be given to the crisis points for carers as well as the person with dementia. It is important to acknowledge that carers may also experience crisis points and they need to be able to access appropriate services during these times.

Access to tailored respite and day care

Forum participants stated that access to tailored respite and day care play an important role in supporting individuals living with dementia and carers:

• Access to tailored respite and day care services is critical in supporting individuals and their carers. It is considered one of the most useful supports to have available, however staff must be appropriately trained in caring for people with cognitive impairment and dementia.
• Some consumers commented that they would be prepared to pay for more tailored respite programs as this type of support is invaluable.
Financial contribution to supports
There were not consistent views amongst forum participants regarding the issue of financial contributions by individuals. However, forum participants were of the view that we need to be careful that the pricing signals going to market do not preclude people from accessing services when needed:

- In general, consumers commented that they would pay for as much as they could afford. Specific services or programs that were identified included: carer support groups, respite, and case management or key workers.
- In order to ensure equity, means testing for a user-pays system could consider the stage of disease. However, forum participants did not specify which stage of dementia should take precedence in a user-pays system.
- However, there were concerns expressed that a user-pays model may exacerbate inequity of access to services across states, territories and local catchments depending on the demographics of the area. There is a need to ensure that those cannot pay are not further marginalised.

Importance of end-of-life transition
Forum participants recognised that efforts on improving the early stages but that the latter stages, including the end-of-life are also important:

- Eighty per cent of palliative care is delivered to people with a malignancy. It is extremely difficult to access good dementia trained palliative care.
- Pain is not well diagnosed in people living with dementia and more effort needs to go into palliative care to ensure adequate pain relief.

3.4 Written submissions
As noted in Section 2 Approach, the National Aged Care Alliance, the Aged Care Sector Committee, and consumers who were unable to attend on the day were invited to provide feedback through written submissions. Six submissions were received. The submissions echo many of the themes raised by Forum participants on the day, particularly reiterating:

- early intervention and community awareness is essential;
- more support for carers, particularly tailored respite and day-care;
- better and flexible support across transitions; and
- systems navigation is important

As well, common across many of written submissions was the need for a better understanding among consumers of what allied health professionals (for example, exercise physiologists, dieticians, speech pathologists) can offer in the care of people living with dementia. The submissions argued that allied health services can support independence and reablement and help improve quality of life for both the person living with dementia and their carer.
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