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**PUBLIC CONSULTATION –  
REDESIGN OF DEMENTIA  
CONSUMER SUPPORTS**

**SUBMISSION FROM  
DEMENTIA AUSTRALIA**

**NOVEMBER 2017**



## INTRODUCTION

Dementia Australia welcomes the opportunity to provide input to the Department of Health's Public consultation on the redesign of dementia consumer supports (the consultation).

**Dementia Australia (DA) is the leading voice for people living with dementia, their families and carers in Australia.**

Our trusted position ensures that we understand the needs of people living with dementia and their carers, particularly the specific needs of people from diverse and vulnerable groups. Dementia Australia's significant experience in supporting people living with dementia across Australia spans more than thirty years and means our organisational insight is augmented by strong networks that allow us to capture and elevate the consumer voice.

Dementia Australia provides the 'first line' response for people living with dementia, carers and families in the community.<sup>1</sup> Our Helpline supports people on a daily basis to deal with all stages of dementia and has received over 37,000 calls last year alone, averaging more than 3,000 call per month. Dementia Australia provides evidence-based information and resources, early intervention programs, carer education and support programs with over 8,000 combined sessions delivered over the last financial year.

**We acknowledge the issues outlined in the consultation paper and understand Government requires changes in the way support is provided to consumers.**

The care and support of people with dementia is one of the largest health care challenges facing Australia. Dementia is now the leading cause of death for women in Australia, and the second leading cause overall, with projections by the ABS estimating it will be the leading cause of death in Australia within the next 5 years.<sup>2</sup> There are more than 410,000 Australians living with dementia. By 2025, the number of people with dementia is expected to increase to more than 530,000. Without a medical breakthrough, the number of people with dementia is expected to be 1.1 million by 2056.<sup>3</sup>

Dementia Australia acknowledges the issues outlined in the Consultation Paper and understands that Government requires adaptations to the way that Australians living with dementia are supported. Many of the issues raised in the Consultation Paper have been discussed previously in several forums, including the Ministerial Dementia Forum and the Aged Care Legislative Review, led by David Tune. We understand that the Australian Government is committed to ensuring that all consumers have greater awareness of

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<sup>1</sup> Original DBMAS model, developed against Brodaty's triangle, was that DA does lower level BPSD, DBMAS does middle tier and the APMHTs and (now) SBRT does higher order BPSD

<sup>2</sup> Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online.

<sup>3</sup> The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017) *Economic Cost of Dementia in Australia 2016-2056*.



dementia, including timely information, early support, and access to high-quality, culturally appropriate aged care services, regardless of their background or location. As the incumbent organisation providing contemporaneous dementia support services that are strongly informed by our broad ranging consumer network, we also understand how the system needs to change in order to achieve these outcomes and to best support people living with dementia and their carers.

**As the leading voice for consumers, we understand how the system needs to change.**

Dementia Australia has been delivering the Australian government-funded National Dementia Support Program (NDSP) for the past 12 years. The services have provided much needed pre- and post-diagnosis support, including dementia specific information, early intervention programs and episodic support such as carer education, counselling and support groups. Through this program we've created linkages to other services, such as government funded supports, residential aged care, the Dementia and Behaviour Management Advisory Service and other community based programs.

We've seen the benefits of well-timed information and early intervention, and we know there is a need to increase timely diagnosis, early support and educational programs, including enablement programs for people living with dementia. We see the opportunities in expanding the links with Primary Health Networks and telehealth providers, and of providing access to information and support via the extension of Helpline hours, providing face to face support as well as telephone and other web based interventions.

NDSP is the foundation for dementia community support. It provides consumers with an accessible, impartial, timely, and evidenced based support service. With the current services, systems, network linkages, infrastructure and staff expertise this package of supports could be expanded to deliver a national dementia care navigator model.

The redesign of dementia consumer supports aims to look at the consumer journey and examine which supports can effectively and efficiently support people living with dementia and their support networks. It will connect people living with dementia, their families and carers with services that may assist and set them on the right path to live well with dementia. It is important to acknowledge that the dementia journey is complex and people living with dementia and carers interact with many different services and supports. The interaction between these different supports and services (including early interventions, carer supports, and information and awareness activity) requires a holistic and coordinated approach and continuity of support.

We have outlined below the changes we would recommend for each service area outlined in the redesigned suite of dementia community supports.



- **Information**

Services should direct people to appropriate existing supports, e.g. My Aged Care and the Carer Gateway, but also to more localised supports that may not be part of mainstream offerings. The National Dementia Helpline provides an initial and continuous support service for people living with dementia, carers and families, including access to and provision of evidenced-based resources.

- **Awareness**

A more targeted awareness and stigma reduction program is needed. The campaign will target trusted and informed intermediaries (GPs, Nurses, AHPs, etc.) who can in turn more efficiently direct consumers to an entry point to services, influence attitudes and awareness of dementia in and out of the health system.

- **Outreach**

There is a need to significantly improve accessibility by recognising diversity in dementia and acknowledging that marginalised and vulnerable people have difficulty connecting with local services. Outreach services and programs should leverage off existing trusted local health and social support networks and ensure there is targeted, culturally appropriate education and support.

- **Intervention**

There is a need to increase the reach of services. Interventions should include information, planning, and counselling, delivered in a flexible, individualised way, in order to support access for all consumers impacted by dementia, including those in regional and remote areas and from vulnerable groups.

We note that the redesign of consumer supports and consequent restructure of the funding, as outlined in the consultation paper, suggests a core goal is an increase in the number of people receiving dementia community supports. However, Dementia Australia is concerned that the current funding envelope is not sufficient to support the more than 400,000 people already experiencing the symptoms of dementia let alone address the growth rates projected over the coming years.

**Dementia Australia has developed a proposed model for Dementia Supports that focus on the changing needs of consumers.**

Dementia Australia's submission is focused on ensuring that the redesigned suite of dementia consumer supports continues to deliver high quality, individualised specialist support to this vulnerable cohort. Importantly, the approach should address the changing needs of consumers and acknowledge the importance of integrating dementia specific supports with other components of the health system. Dementia Australia broadly supports the elements presented in the consultation paper; however the key messages and experiences recounted to us by consumers and other stakeholders must inform the



redesign of dementia supports for this important suite of services to continue being impactful.

In order to best support people living with dementia to continue to live well, there are 4 key elements that must be addressed through the redesign of dementia community supports:

### **1. Information and awareness**

Increasing community knowledge and awareness of dementia is vital. A national dementia helpline already provides specialised support at all stages of dementia, including referrals to local services and supports for people living with dementia, families and carers. But this is still relying on community awareness of dementia and the need for support, which as research has shows is still quite low. Thus there is a need for complementary awareness raising activities on a larger scale that collaborate with community influencers and groups – from researchers, specialists and GPs, to individuals, families and community groups.

### **2. Timely diagnosis and post diagnostic support (including early intervention)**

Early intervention is fundamental for people living with dementia, their families and carers. While the current suite of dementia community supports do provide consumer centred early intervention supports, much more needs to be done to enhance current levels of access. We need to support a timely diagnosis with linkages to Primary Health Networks (PHNs), GPs and specialists, followed by appropriate early intervention services which encourage and promote independence and quality of life.

### **3. Building capacity and recognising the diversity in dementia**

General mainstream services are not adequate to meet the needs of people living with dementia and it is imperative that specialist supports continue to be provided. Specialised capacity building is also required to ensure service providers understand diversity in dementia, including flexible and adaptable services for regional, rural, LGBTI, CALD, and Indigenous communities, as well as appropriate support for those who are living on their own with dementia.

### **4. Access to ongoing care and support, including carer support**

In order to best support the person living with dementia, it is essential that their carers and families are also supported. To achieve optimal outcomes, there must be appropriate, complementary support for families and carers such as counselling, education and information.

Dementia presents a huge challenge to all Australians. We know awareness and understanding about dementia is still alarmingly low. We know the prevalence is growing. We know dementia is the second leading cause of death of Australians and the leading



cause of death of women in Australia. Sadly, we know it is fatal and there is no cure, however with the right support people can live well with dementia. Therefore we must ensure that the primary aim of the redesign is to enable people living with dementia, and their carers and families to access critical community based specialist support.

**Dementia Australia has a unique understanding of the issues and is evolving to best serve people living with dementia, their carers and families**

As experts in dementia, Dementia Australia is the sector leader in providing evidence based, consumer-centred dementia specialist support. The wealth of experience and strong relationships that have been developed across our national networks allows Dementia Australia to provide advocacy and support without conflict of interest.

To this end, Dementia Australia has fundamentally changed our organisation's structure. From an entity that operated as federation of state-based member associations, known collectively as Alzheimer's Australia, we are now one unified organisation called Dementia Australia. With more than 100 types of dementia – Alzheimer's disease being but one – our new name reflects that, as the peak body, we are here for people of all ages, living with all forms of dementia, their families and carers.

This unified structure enables the delivery of consistent support services into the future, strengthens our capacity for advocacy that is informed by a wide array of consumer experience and enhances the organisation's ability to raise awareness, fundraise, and facilitate research and education into the prevention, delay and cure of dementia. Dementia Australia is now a more agile and responsive entity which seamlessly and sustainably continues to deliver crucial support services with a renewed commitment to supporting people living with dementia, their families and carers.

From a grassroots community of passionate carers around Australia we have evolved into the leading independent organisation providing a voice for people impacted by dementia.

These credentials tell us that the redesign of dementia consumer supports should be developed through the lens of consumer experience and that it is vital, as a starting point, to examine the required supports and services to assist people living with dementia and their support networks. At their core, the redesigned supports should aim to connect people living with dementia to the health services that best meet their needs and enable them to live well with dementia.

Dementia Australia's individualised yet integrated model leverages local networks and supports, helps build the capacity of the sector and provides important dementia specific services. An individualised approach to care involves understanding, not only the unique characteristics of the disease, but also what it means for that person to live well with dementia and how they can be supported to do so. This involves focusing on the social, emotional, physical, and health needs of the person with dementia as well as their carers and family members.



### **Question one**

***Given the existence of an information line for several years and the continued ongoing low dementia literacy rates, are there additional supports that the information line and website can better leverage to increase dementia literacy in the community?***

The results of a recent Ipsos omnibus survey conducted for Dementia Australia highlight the poor dementia literacy amongst the general public.<sup>4</sup> Only 17 per cent of survey respondents correctly ranked dementia as the second leading cause of death. More than half of the respondents did not understand the relationship between Alzheimer's disease and dementia, while almost 40 per cent of respondents did not know that dementia is not a normal part of ageing.

While we acknowledge this poor dementia literacy and the need to address it, equally we need to be clear about purpose and audience of the information line and website. As noted throughout the consultation paper, the intent of the information line is to support people impacted by dementia. As such, the effectiveness of the information line cannot be judged by dementia literacy in the broader community. A member of the general public who is not impacted by dementia will not call a dementia information line or visit a dementia website. To increase dementia literacy in the general community, a broader awareness campaign is required.

We also note that the proposed intent of this redesigned component, as presented in the consultation paper, seems to be information based rather than being educative in nature and offering support and counselling, which is the key features of what is currently offered through the current National Dementia Helpline and Referral Service. If information is the primary purpose of the redesigned service, consideration must be given to expectations about call durations as well as roles and qualifications of the information line staff.

An independent evaluation<sup>5</sup> of the current National Dementia Helpline found high rates of satisfaction with the service. Callers were particularly appreciative of the emotional support provided by the dementia advisors who staff the Helpline.

*“Wonderfully supportive people on the line. A shoulder to cry on during my first call. Hardest I've ever had to make as this is the first time I've opened up about my concerns over changes in my husband's cognitive ability and challenging behaviours. They made it*

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4 Dementia Australia (2017) *Awareness and Understanding of Dementia in Australia*, Research Report October 2017 available at <https://www.dementia.org.au/files/media/2017-IPSON-report.pdf>

5 ARTD Consultants (2016) *Evaluation of the National Dementia Helpline and Referral Service*, Alzheimer's Australia NSW, Final Report August 2016



*much easier for me to talk and gave me some ideas on next steps to take. [Carer, paper survey]*

*"It's the only place I can call! I just appreciate that there's somebody I can talk to outside of medical people who haven't been so helpful. I'd certainly recommend it to anyone else." [Person with dementia, phone survey]*

*"The person on that night gave me a wonderful explanation that set me at peace, I was so frightened, she was marvellous. I would appreciate any new information at any time to help me." [Person at heightened risk of dementia, paper survey]*

Dementia Australia therefore recommends that the redesigned dementia supports continues to provide an educative and supportive helpline rather than switching to an information-only model. It is also important that the Information line has close links to early intervention supports, especially so that callers are referred to the services they need in a timely manner. It is vital that we support people by providing information relevant to the particular stage of their dementia journey (e.g. before they are eligible for aged care services).

Moreover, we need to consider the efficiency of existing national, mainstream service provision as well. Anecdotal reports to Dementia Australia from people with dementia and their carers suggest that My Aged Care (MAC) and the Carer Gateway are not yet functioning as well as they should be with regard to dementia. There is a gap between intent and practice in MAC – arguably it does not offer accessible and seamless support for dementia consumers. The proposed dementia specialist information line, not MAC, could therefore serve as a more efficient and effective first port of call for anyone impacted by dementia given the need to provide specific and unique information and the high level of dementia literacy to be able to do so.

Additional supports that the information line and website can better leverage to increase dementia literacy in the community could include:

- An established pathway with the primary health sector, specifically GPs, to facilitate increased early contact with services.
- Targeted promotion of the information line and website to special needs groups, including culturally and linguistically diverse communities and Aboriginal and Torres Strait Island communities.
- Stronger links with My Aged Care and the Carers Gateway to facilitate increased referrals to the dementia information line and website to ensure that people receive the specialist advice and information they require.





## **Question two**

**Noting the outreach services outlined at 3.4, are there further considerations needed to better support:**

- **consumers with low IT literacy or lack of access to IT infrastructure?**
- **special needs groups, especially with people with low literacy levels, from Culturally and Linguistically Diverse backgrounds or from regional, rural and remote areas to have equity of access to these core information supports services?**

Dementia Australia has many concerns with the proposed services outlined under section 3.4, which we detail below. However, we would also emphasise that the overarching objectives of the outreach component should be that it spans the continuum of a consumer's dementia journey, and that this cannot be limited to any distinct 'key stages' of information requirement. Consumers often need support even before they have a diagnosis of dementia and at several points as they transition through different settings of care. Foundation support, as the information component is rightly called, thus has to be across the spectrum of consumer need, at any and every stage of their journey, irrespective of whether it is deemed 'key'.

With regards to the specifics outlined in the consultation paper, it is important to offer the caveat that the outreach services outlined in section 3.4 include a variety of elements that are too broad in scope. Based on our experience, Dementia Australia would argue that the scope is not achievable with the proposed \$2 million of funding. This section of the paper needs to be clarified, refined and targeted. Furthermore, many of the outreach activities described in this section need to be achievable in regional parts of the country but they also need to occur in metropolitan/urban areas of Australia.

Another point requiring clarification is whether younger onset dementia is included as a special needs group, especially carers of people with younger onset dementia, whose information and support needs may not be addressed appropriately through the National Disability Insurance Scheme (NDIS). Dementia Australia has long believed that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception.

However as the NDIS rollout has progressed, many people living with younger onset dementia have faced barriers in accessing a plan or have received insufficient plans that adversely affect their quality of life and place some at risk of avoidable hospitalisation. Our current experience of ongoing transition activities highlight that there are several areas of concern that need to be addressed before the transition can be successfully completed.



The lack of planning and rush to enlist participants has manifested in the progressive and complex needs of people with neurodegenerative diseases like younger onset dementia being overlooked or insufficiently addressed, and Dementia Australia is concerned that unless transition issues with the NDIS are resolved, people with younger onset dementia will need to look at other avenues for community based supports. This could potentially have an impact on the client profile of consumers accessing dementia community supports as well.

Also unclear is the extent to which the needs of Aboriginal and Torres Strait Islander communities will be addressed, given this cohort is not mentioned specifically in this section or elsewhere in the consultation paper. The prevalence of dementia in Aboriginal communities is 4-5 times that of the general Australia population. A dedicated, funded service reach to these communities is required to ensure the availability of responsive and culturally respectful services that make a difference for people living with dementia in Aboriginal communities.

Other equity of access questions that must be answered in any redesign of dementia supports relate to information sources and communication mechanisms.

Telephone support is vital for consumers with low IT literacy or lack of access to IT infrastructure. Funding is also required to support face-to-face delivery and other flexible models to provide tailored service delivery that meets the needs of particular consumers and communities.

Pop-up information events and outreach activities within communities are essential in raising community awareness of dementia and reducing stigma. Dementia Australia is receiving an increasing volume of requests for community awareness activities, including community talks and presentations, memory van visits etc. These types of important activities do not appear to be within the scope of the dementia community supports program as it is detailed in the consultation paper.

Best practice models for people from CALD backgrounds include the use of bilingual workers (over interpreter services) and partnerships with CALD agencies with specific funding to properly support their involvement. The requisite level of involvement from these stakeholders is not achievable within the proposed funding envelope.

It is also important that specialist service responses are available early, particularly as a way of developing positive relationships with the service sector that are likely to be useful at various touchpoints throughout the dementia experience. The early connection to services can provide useful information about accessing the right services in a timely manner and may assist to avoid crises through lack of awareness of supports. Early intervention is also important to provide family and other informal supports with good information about dementia and effective principles of intervention and care.



### **Question three**

***The Australian Government has providing support for dementia awareness and stigma reduction activities for over a decade. However, less than 30 per cent of those people living with dementia who access Australian Government funded dementia consumer supports programs, heard about the supports from a health professional.***

***Noting the proposed awareness activities outlined at 3.3, given the continuing low rates of dementia literacy among health professionals are there other specific supports that would encourage self-management, independence and reablement to ensure people recently diagnosed with dementia connect to the available support services early?***

General Practitioners (GPs) and other health professionals are at the frontline of primary health care and should be referring their patients with dementia to support programs and services. The diagnosis of dementia is different from that of many other diseases as there is no simple test that provides a definitive diagnosis. Instead, cognitive assessment must be combined with information from family members, medical tests and self-reporting in order to determine a diagnosis. As a result, many GPs find it difficult to differentiate dementia from the normal changes in memory and thinking associated with ageing.

This high level of non- and late-diagnosis may be due partly to a lack of adequate and specific education and training on dementia for GPs and other primary health care professionals. There may also be a resistance by some GPs to provide a diagnosis of dementia due to the stigma attached to the disease, and the terminal nature of the condition – which is further complicated by the message that there is no known cure. In addition, a comprehensive cognitive assessment is time consuming and GPs may consider that they are not adequately remunerated for this time.

The continuing low rates of dementia literacy among health professionals needs to be urgently addressed, and the redesigned suite of consumer supports should address this need. Medical and allied health students should receive education about dementia and there needs to be ongoing workforce training to reduce stigma of dementia and increase awareness of support services. The 2011 report *Timely Diagnosis of Dementia*<sup>6</sup> highlights opportunities in this area as well as gaps.

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<sup>6</sup> Phillips, J., Pond, D. & S Goode (2011) *Timely Diagnosis of Dementia: Can we do better*, available at [https://www.dementia.org.au/files/Timely\\_Diagnosis\\_Can\\_we\\_do\\_better.pdf](https://www.dementia.org.au/files/Timely_Diagnosis_Can_we_do_better.pdf)



As the question remarks, only 30 percent of people who access consumer supports are referred by health professionals. To address these issues, the awareness component requires the development of strong and effective referral pathways from diagnostic points – GPs, geriatricians, memory clinics – and this needs to include the dementia specialist website and information as part of referral pathway following diagnosis.

It is, however, important to note that improved knowledge of dementia in the healthcare sector is only one part of the solution. Consumers often report to Dementia Australia staff that complementary information to that provided by the GP is vital. One consumer caring for her mother with younger onset dementia identified that she had contacted another organisation but was disappointed that she did not receive the support and assistance she required. She then made contact with Dementia Australia and we were able to provide her with information and support she felt she needed. She commented that

*“Alzheimer’s Australia (DA) was honest, open and supportive. A nurse and educator answered every single question and posted me information packages which were so absolutely comprehensive and useful. I thought, why can’t the GPs do this? Why don’t people know this? It shouldn’t be secret information!”*

Another carer commented that:

*“The most significant and important impact on us was the help we received from Alzheimer’s, it gave us what we desperately needed in our shocked state and showed us how to proceed with life”*

Dementia Australia believes there is significant evidence pointing to the need for a system navigator role to support people with dementia and their carers and families to access the appropriate services and supports when and how they need them. Finding quality dementia care and support can be incredibly complex and challenging. The overwhelming feedback from people impacted by dementia is that support to navigate the care and support system is imperative and this message was also heard at the 2016 Ministerial Dementia Forum. This role is the missing element to the current service landscape and is necessary to ensure that the capacity to effectively support people living with dementia throughout their experience, particularly in remote regions, is improved.

Listed below are some other ideas for supports that could encourage self-management and independence to ensure people recently diagnosed with dementia connect to the available support services early:

- A community development approach to build relationships with local Memory Clinics and similar services so as to increase referrals to appropriate and timely supports for people with dementia and their carers.



- A service that draws on the significant learnings from Victoria's younger onset dementia "Care Consultant" role, which has been successful in building capacity within the sector via targeted educative and consultancy work. The Care Consultant is essentially a specialist who works with providers to better provide care to clients with younger onset dementia. For example, a care consultant can work with a physical trainer at the YMCA to create a gym program for younger clients with dementia. This could involve not just training the gym trainees but a range of other staff, including the reception staff and then building a suitable exercise program that meets the needs of the person with younger onset dementia.

### **Misplaced focus on 'self-management'**

While the consultation paper does not seek input around point 3.1, the objectives of the redesigned consumer supports, Dementia Australia is concerned with the intention of the aim *"to connect people living with dementia, their families and carers with services that may assist and set them on the right path to self-manage."* Dementia Australia and our consumers are strongly supportive of the current move to consumer directed care (CDC) and welcome reablement approaches; however, the idea of self-management assumes a fundamentally good level of function, or an ability to rehabilitate to the same. There is a need to be careful with the idea of people with dementia self-managing as, by virtue of the progressive cognitive nature of the condition, they will need increasing support as time goes on to live well with dementia.

Self-management also requires some level of insight, which is a quality that is impaired by dementia and not able to be rehabilitated. Similarly, carers are often also not in a position to fully self-manage, since high numbers of them are elderly and they may be dealing with chronic conditions themselves. Interestingly, neither the concept of self-management nor reablement were raised as being important to consumers participating in the several public consultations held with people with dementia, their carers or stakeholders working in the industry to discuss the redesign of services by.

Dementia Australia therefore reiterates that people with dementia have a progressive neurological and terminal disease that runs counter to the 'traditional' trajectory of a 'self-managed' approach: that is, an ability to enhance independence and reablement through a more effective engagement of services. For someone with a neurodegenerative disease, care needs inevitably increase over time regardless of how well they are supported. The redesigned suite of consumer supports needs to acknowledge this and balance independent goal setting with advance care planning. People with dementia should also have pre-planning education and support to assist them as they consider their future needs that go beyond the 'early intervention' support needs.



#### ***Question four***

#### ***Are there any other groups which should be included in the targeted awareness and stigma reduction campaign and how should they be prioritised?***

The targeted awareness and stigma reduction campaign should include GPs, practice nurses and other primary health professionals. The acute care sector should also be targeted. As noted in our response to a previous question, primary health care professionals, including GPs, may also lack information and confidence with regard to treatment and referral pathways for people with dementia. The development of clear referral pathways to specialist dementia services would assist in this area.

Primary health care nurses also have frequent contact with older people in general practice and other health care and community settings; however, their role in relation to the assessment, diagnosis and management of dementia is not well defined and could potentially be expanded. Community health nurses/district nurses often play an important role in assessment and referral, in helping people with dementia to manage their condition and live safely in their own homes for longer, and in assisting with issues such as medication management. There is potential for this role to be broadened and better supported across the primary health care nursing profession (including general practice nurses), within the context of the primary health care team.

But most importantly, in order for any awareness program to be successfully targeted to health providers such as GPs, the government will need to provide some incentive to participate in, engage with and respond to such dementia awareness activity/information/education. Past attempts to provide this information and message particularly to GPs has been limited by their lack attendance, especially as they have no mandated outcomes or outputs around dementia care. There needs to be some responsibility for quality dementia care recognised by health professionals and this will need to be influenced by government policy.

On page 6 of the consultation paper it is stated that the awareness and stigma reduction campaign will target trusted and informed intermediaries who regularly interact with people at risk of developing dementia or recently diagnosed, including General Practitioners, Pharmacists, Registered and Enrolled Nurses, Allied Health Professionals and so on. It is the view of Dementia Australia that this list of 'trusted and informed intermediaries' needs to be expanded beyond just health professionals to include other trusted members of communities. While GP's play an important role and are recognised as the 'gatekeepers' for access to appropriate care, there is not much recognition about the fact that people would seek alternative sources for early information and support if there were better levels of awareness of their availability.



Thus the campaign should also target professions such as police officers and spiritual leaders who are held in high regard in many communities. Such an approach will also be in line with the World Health Organisation's Global Action Plan on Dementia, which specifically urges member states to consider dementia as a public health priority.

Proposed actions for member states are to:

*Develop programmes, adapted to the relevant context, to encourage dementia-friendly attitudes in the community and the public and private sectors that are informed by the experiences of people with dementia and their carers. Target different community and stakeholder groups, including but not limited to: school students and teachers, police, ambulance, fire brigades, transport, financial and other public service providers, education*

World Health Organisation, 2017<sup>7</sup>

People at risk of developing dementia also need to be targeted in a separate campaign under a separate funding stream, which is an important activity that will complement the aims of the dementia community support program.

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<sup>7</sup> World Health Organisation (2017) *Draft global action plan on the public health response to dementia*. Access online here.



### **Question five**

#### ***Are there other factors to consider in ensuring services are appropriate and accessible to the most vulnerable or marginalised people living with dementia?***

Dementia Australia notes that the consultation paper currently only identifies people from culturally and linguistically diverse backgrounds (CALD) backgrounds under section 3.4 as in need of targeted outreach. Dementia Australia recognises that people from CALD backgrounds, as well as Aboriginal and Torres Strait Islander backgrounds, people who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI), and those individuals who are living alone, socially isolated, or homeless, as well as people with other disabilities or co-morbidities face a unique set of challenges in relation to a diagnosis of dementia and ongoing access to appropriate services.

One in five individuals with dementia is from a cultural and linguistically diverse background. Aboriginal and Torres Strait Islanders have 3-5 times the risk of developing dementia than non-Indigenous persons. In 2016, there were as many as 118,000 individuals with dementia living alone in the community.<sup>8</sup> Thus Dementia Australia has always ensured a focus on meeting the needs of special needs groups across our spectrum of service delivery and have developed a range of innovative services and supports to better meet the needs of these groups. We continue to provide input to the ongoing determination of policy in the area, with our submissions to the Review of Ageing and Aged Care Strategies for people from CALD backgrounds,<sup>9</sup> National LGBTI Ageing and Aged Care Strategy Review<sup>10</sup> as well as the consultation to inform the development of the aged care diversity framework.<sup>11</sup>

However, this approach is not reflected across the sector. Although dementia – as well as a broad range of ‘special needs’ – is treated as ‘core business’ in an aged care policy context, the operational reality is such that providers are constantly trying to balance a broad range of specialist care needs with clinical efficiencies and financial sustainability. Moreover, the unique cultural and environmental needs of these cohorts needs to be addressed through service delivery, which requires education, time and funding to support service providers in adapting their approaches. Without specialised support, vulnerable and marginalised consumers are often neglected. Therefore, further targeted investment – and support for such investment – is required to ensure aged care providers are better

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8 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017) *Economic Cost of Dementia in Australia 2016-2056*.

9 Dementia Australia (2017a). *Submission to the review of National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*.

10 Dementia Australia (2017b) *Submission to the review National LGBTI Ageing and Aged Care Strategy Review*.

11 Dementia Australia (2017b) *Submission to the consultation to inform the development of the aged care diversity framework*.





prepared to meet the needs of people from special needs background who are impacted by dementia. While this may be the intent of higher level documents such as the proposed new Diversity Framework, in practice this also has to be recognised and supported through increased funding across service delivery, and as such this component should be integrated more consistently and overtly across the redesigned suite of consumer supports.

Targeted outreach that addresses explicit issues is therefore an important distinction which should be added to the outreach component of the redesigned supports. So far, the NDSP has funded development and translation of help sheets and resources into languages other than English, stimulated research and policy development on topics relevant to a range of consumers, and supported consumer engagement and priority setting through special needs advisory groups. NDSP funding has also enabled Dementia Australia to tailor the core components of the NDSP program (counselling, support, early intervention) to suit the needs of special needs groups. The Service Delivery Pathways Project (SDPP) also developed new and innovative services approaches for a number of special needs groups; however the short-term funding model has limited the ability of these approaches to be developed or delivered over the longer term.

Despite these barriers, the SDPP projects have increased equity of access to information and services to people from special needs groups around Australia including Aboriginal and Torres Strait Islander peoples, people living in remote areas, people from culturally and linguistically diverse backgrounds, people experiencing or at risk of homelessness, the lesbian, gay, bisexual, transgender and intersex communities, people with dementia living alone and prison communities. The legacy of the SDPP projects has been the successful outcomes that can be achieved through innovative and flexible approaches that are aligned to the needs of special needs groups.

Although we understand the need for service provision to be fiscally responsible, the precondition that it will “also be necessary for the provider of such services to ensure they are not duplicating national service functions of My Aged Care and the Carer Gateway” has the potential to limit innovation and specialised services for people with special needs. There also needs to be more clarity around the use of the term ‘duplication’. For instance, if a service is provided by My Aged Care but is not accessible to a special needs group or easy for them to use, then there is a need to ‘duplicate’ – or really to adapt – that service so that it can be provided in a way that is readily accessible.

The intent of the redesign should therefore be more focused on a consumer’s needs and the related outcome where appropriate. This has already been noted by high level reviews like David Tune’s legislative review that notes:

“...many stakeholders expressed concern that the inaccessibility of the [My Aged Care] website can be a barrier to accessing aged care services. This is because the ability of a consumer or their support network to access the website is dependent on their computer literacy and proficiency, whether they can physically access a computer and the internet,



and the accessibility of the website content. These barriers may be particularly prevalent for some population groups, such as people who are homeless, the vision impaired or people with dementia. Barriers are also a greater concern in rural and remote areas. These concerns are valid and need to be addressed.”

For vulnerable and marginalised groups living with dementia, mainstream portals such as My Aged Care and the Carer Gateway may be inappropriate in many circumstances. The intention behind Outreach as proposed in the consultation paper should therefore have a *no wrong door* policy, so that consumers can be referred onto the services they need through any channel. Consumer need should determine access and this should not be limited by curtailing modes of access.

In Dementia Australia's view, therefore, the paramount consideration in determining outreach needs should be how best they can be met. Dementia Australia also recommends that as a first step and where appropriate, the aim of the redesigned consumer support program should be to develop capacity within stakeholders that are already closely linked into vulnerable and marginalised communities. For instance, Aboriginal Community Controlled Health organisations should be educated on dementia services so that they are providing support to meet individual and community needs. This will assist in the uptake of services by members of the community and assist in ensuring the cultural appropriateness of the services provided.



### **Question six**

#### ***Will this model of redesign services embed improved access to services and outcomes for people living with dementia into the future?***

Dementia Australia has demonstrated its ability to work effectively as a national organisation and undertake multijurisdictional service delivery through the provision of nationally consistent NDSP programs such as Living with Dementia, streamlined quality frameworks, and increased efficiency of the National Dementia Helpline.

Through our experience in delivering the NDSP for over a decade, it is clear to Dementia Australia that services for people with dementia are only effective when they span the continuum of care and support, from prevention and early intervention to timely diagnosis, carer and client support in the community and to high level end of life support. The focus of the redesign should therefore be to ensure a holistic approach to dementia care that begins with raising awareness amongst the general population, and spans the provision of services to people with dementia, their families and carers from point of diagnosis, through to appropriate end of life care.

The ability for NDSP to provide services to a broad spectrum of individuals including carers, and those without a clear diagnosis of dementia, has been a hallmark of the program and an essential component to appropriate support. It will be important to ensure that the redesigned supports continue to be provided across the spectrum and are not limited only to individuals with a diagnosis of dementia.

An individualised approach to care involves understanding not only the unique characteristics of the disease but also what it means for that person to live well with dementia and how they can be supported to do so. This involves focusing on the social, emotional, physical, and health needs of the person with dementia as well as their carers and family members.

Evidence shows that specialised and targeted programs and services can lessen the burden and reduce costs across the broader health and aged care sector in relation to dementia. Data released by Dementia Australia earlier this year shows that the cost of dementia in Australia in 2016 was \$14.25 billion, which equates to an average cost of \$35,550 per person with dementia,<sup>12</sup> and we know that residential aged care is the most expensive component of these costs. So we must enhance the reach and quality of community based supports if we want to reduce the fiscal impact of dementia.

Another significant issue omitted by the consultation paper is the need for information and support for advanced dementia, particularly the need for high-level end of life support.

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<sup>12</sup> The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.



While information and support through early intervention are important, end of life support and palliative care information is just as vital to many people living with dementia.

Therefore, DA believes that the top three priorities that should be addressed through this Redesign process should be:

1. Addressing the current market failure through programs and services that are responsive, integrated and flexible. Data released this year has shown that consumers are already waiting longer than 12 months to access Home Care Packages,<sup>13</sup> with around more than 53,000 consumers still awaiting a package as on 30 June 2017.<sup>14</sup> This is an unacceptable amount of time for vulnerable consumers with dementia to wait, and underlines the urgent need to strengthen alternative dementia specialist community support for this cohort. This is necessary to ensure that people do not fall through the gaps and enter residential care prematurely. A holistic approach to care, services and support thus needs to go beyond the options provided by My Aged Care and federally funded aged care services (Home Care Packages, Commonwealth Home Support Programme). Specifically, dementia specific community based programmes need to be adequately funded to ensure that specialist care can be accessed by people impacted by dementia, their carers, families and communities.
2. The aim of the redesigned consumer supports should align to an overarching framework that focuses on:
  - Information and Awareness and risk reduction;
  - Timely diagnosis and post diagnostic support (including early intervention);
  - Building capacity and recognition of diversity in dementia;
  - Carer support; and
  - Access to ongoing care and support.
3. Ensuring truly effective service responsiveness that will require integrating specialised expertise and understanding of dementia into mainstream service delivery so that it can be more effective in meeting the needs of people with dementia.

Implementing these priorities requires leadership, funding certainty, and flexibility in programme delivery and service innovation to meet changing and growing demands.

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<sup>13</sup> My Aged Care Operational Update by Department of Health on 31 October 2017.

<sup>14</sup> Department of Health (2017). *Home Care Packages Report*. Accessed online at <https://gen-agedcaredata.gov.au/Resources/Home-care-packages-program-data-report-2017>



### **Question seven**

***Current early intervention supports only reach around 1 per cent of people recently diagnosed with dementia. The combined emphasis of the Information (3.2) and Awareness (3.3) elements of the dementia consumer supports are expected to reach a substantially higher proportion of the diagnosed population. Are there other elements that should be considered in order to increase the proportion of the diagnosed population who will know about and want access to these services?***

NDSP has been able to provide services and supports to family members and carers of people living with dementia, who are often crucial in the early intervention phase and facilitate ongoing community based support for the person living with dementia. Besides support for the person living with dementia and their families or carers, NDSP has also built community awareness and education, which has a much larger impact on early intervention support than has been captured in the one percent estimate.

While we acknowledge that there is much more to be done in terms of extending the reach of consumer supports, this also needs to be supported by evidence based, well-funded and strategic education and awareness across the sector. Experience in delivering the NDSP has also shown Dementia Australia that greater awareness and understanding amongst clients is hampered by the fact that the need for services during the journey with dementia is highly personal and often only recognised at crisis points.

Under NDSP, Dementia Australia has provided a different and unique programme of services and supports to people with dementia that are not seen in any other funding streams. These programs have been developed in direct response to consumer needs, crucial to which is the need for the person with dementia and their carer to access services together and throughout their journey as required. Services offered through these programmes reflect the transitional nature of the course of dementia in that clients have the ability to reconnect with the service as required.

This provides clients the opportunity to receive support on an ongoing basis particularly at times of crisis and change such as when the need for community support becomes apparent, changes in the behavioural symptoms of dementia appear, and transition to care. It is vital that this approach continues to remain a part of the redesigned suite of services.

### **Focus on 'One-off' intervention**

Dementia Australia notes the consultation paper's emphasis on the redesigned consumer supports being limited to providing only '*once-off intervention for those recently diagnosed with dementia, aiming to set them on the right path*'. This would be an inadequate



approach in dealing with the unique and specialist needs of people living with progressive neurological decline and would also run counter to the move to consumer directed care across aged care service delivery.

In Dementia Australia's view, early intervention cannot be limited to a one-off engagement with a consumer. Most of the time, clients that reach out to Dementia Australia via the helpline are facing a crisis situation, with escalating needs for support to enable them to remain in community. There needs to be a balance in the redesigned consumer support services between a preventative/early intervention focus, and support for those with higher levels of need and higher carer stress and impact. Consistent and equitable support across this spectrum is vital. Receiving up to date and ongoing information on one's condition, provided at key points, as well as information on how to manage has been found to facilitate independence in people with dementia.<sup>15</sup> This is backed up through our service delivery, where we have seen that consumers highly regard follow up interventions and the peer support aspect of ongoing engagement.

This was a theme that was also picked up by the NDSP Evaluation report which notes that:

*The overall impression left by the services and interactions with Alzheimer's Australia staff is that their local office is a 'safe place' where they can receive a cup of tea and a great deal of not only practical but emotional support. A common sentiment expressed by clients following engagement with the organisation was that they were doing fine for now but that they were sure help would be there if they needed it, even if they didn't currently know what that help might look like.*

*NDSP Revitalised: Report by Hall and Partner, 2015*

This is also why around a quarter of respondents to a Dementia Australia consumer survey identified peer support as the service that had been most useful to them – making this the highest ranking item amongst respondents to the survey. The following comments come from a 68-year old carer of a wife with dementia:

*"The [Alzheimer's Australia] 'Living with Memory Loss' program...was one of the best things that's happened to us, well certainly to me. It was fantastic...we had to go back every month after the course, for a follow up session. Having done that for six months, we then went into a carers group – therein lies the best thing that has happened to me throughout the whole process. I am still a member of that carers group. Not only did our facilitator have a lot of information, tremendous amount of information, but at least half of the people in our carers group (some of them had been there for 10 years), they had an enormous amount of experience. I would just go there and take notes on all that they*

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15 von Kutzleben M, Schmid W, Halek M, Holle B, Bartholomeyczik S., Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia., Aging Ment Health. 2012;16(3):378-90. doi: 10.1080/13607863.2011.614594.



*knew, everything that came up. That was really really helpful and still today is helpful. I feel I really got all the support I felt I needed and there was always someone to ask a question. Even the people in our carers group that have lost their loved ones now, there is a group of us that still have a lunch together so all that information is never really lost. Within the carers group, there really is all the information you will need. It's very important to have that support, I think for anyone dealing with it and a lot of them find that time in the carers group find that little bit of respite for themselves which is fantastic.”<sup>16</sup>*

The use of the early intervention education program as a conduit into the peer support group in this instance illustrates the value of an integrated and multi-faceted service offering by a specialised provider.

Several carers have reported on the quality of care they receive through our dementia advisors and how helpful they had found them, particularly in connecting them to relevant information and ongoing support. One carer commented that the dementia advisor:

*“has been extraordinary and...wonderful because she keeps suggesting new things for me to try or get advice about...she suggested [the] day care centre so that I could keep working.”*

Clearly ongoing intervention, which includes services and supports for carers should be an integral component of the redesigned services.

## **Removing Carer Support from early intervention**

To enable people with dementia to live at home for as long as possible – which meets their preferences and is also cost-effective for the health and aged care systems – it is critical that their carers are well supported. Research to date suggests that specialist and structured interventions that combine information, education, skills training, and psychosocial therapies led by qualified professionals and delivered over a period of time, with active participation by carers, tend to show the most positive improvements in carer outcomes. Consumers report, and the literature concurs, that provision of support and education for carers, such as that provided through NDSP, significantly increases their capacity to care for the person with dementia at home for longer. This is true for rural and metropolitan carers.

Diluting the focus on meeting the needs of carer groups will have a subsequent impact on the ability of carers to continue to support people with dementia living in the community. In Dementia Australia's view, limiting access to carer support and services to those



accessible through the Carer Gateway is not an appropriate approach to address the specialist, unique needs of carers of people living with dementia.

Most people with dementia and their families prefer that the person with dementia remain living at home for as long as possible, and carer support is a critical factor which currently enables 70% of people with dementia to live in the community. The increasing focus on home care as opposed to residential care, while aligned with consumer preferences, is likely to lead to increased demand for support in the community. The highest level home care packages provide only an average of 14 hours per week of care. This is insufficient for many people with dementia as their condition advances, and additional informal care will be needed. Already there are significant threats to the sustainability of this carer support and we face a looming shortage of carers. The impacts of caring are substantial, and while some carers experience positive impacts, many carers experience negative effects on their emotional, psychological, and physical health, social activities, ability to work and finances.

Carers of people with dementia need specialised support services, which are specific to caring for a person with dementia. Mainstream approaches to education, counselling and other interventions do not meet the needs of many carers of people with dementia.

In order to ensure that people with dementia have access to the support they require there is a need for services that have a specific level of understanding and training in dementia and dementia care. These cannot be provided by mainstream service provision through My Aged Care or the Carer Gateway. Dementia Australia's experience and consumer feedback has shown us that it is not realistic to expect the contact centre staff to have this level of understanding around dementia specialist needs and support requirements.

In addition, the capacity building component of the information provision and the local level advocacy provided by Dementia Australia cannot be replicated by My Aged Care or the Carer Gateway. Given that this support is provided through the journey of the client and/or their carer it would also appear unrealistic that this role could be taken on by any mainstream service provider.

The flexibility around service provision that has been offered by Dementia Australia has also been noted in the Program's Evaluation:

*Clients taking advantage of the counselling service offered by Alzheimer's Australia particularly appreciate the fact that it is offered at no fee, through a number of channels (face-to-face, phone, and even Skype in some jurisdictions), and that there seem to be few, if any, waiting lists. This is seen as being in stark contrast to other counselling services or access to psychologists offered through the health system (where only a specified number of sessions is able to be bulk-billed).*

*NDSP Revitalised: Report by Hall and Partner, 2015*





Feedback from consumers on Dementia Australia services indicated that many carers highly value specialised education targeted to their specific issues and needs. Education was ranked third, after peer support and respite care, in a Dementia Australia consumer survey asking carers which supports had been the most useful to them. As one consumer commented:

*Initially the [Alzheimer's Australia] "Living with Memory Loss" course was very helpful. It assisted with ideas of what to do in the home environment to support my Mum with dementia. The systems my sister and I have instigated are very detailed and required a lot of work and discussion on our part because there is not one size fits all with calendars, signs, prompting mechanisms, visitors book, and other processes but they all worked really well as long as everyone was on board with our needs.<sup>17</sup>*

*Carer perspective on specialised support*

Another consumer comment highlights the importance of specialised and relevant education:

*"[Carer education] is vital in that the Carer needs specialised education and training in order to manage dementia, especially behavioural issues in the FTD [fronto-temporal dementia] area. I found that once I was educated more and learnt new skills to manage my husband's dementia issues, I was more in control and acceptance of the situation came about more quickly. Different dementias need different training, e.g. my husband has Fronto Temporal Dementia, with Semantic and Behavioural variants. This meant comprehension of the language was deteriorating, as well as socially unacceptable behaviour; this requires a different level of training compared with someone with Alzheimer's disease, where there is more of a memory loss. It is also important for hands on Carers to share their experiences in conjunction with a professional educator."*

*Carer perspective on specialised support<sup>18</sup>*

Again, the importance of support groups has also been highlighted in the Evaluation of NDSP:

*Participants in carer support groups viewed them as very helpful, in terms of the emotional support they offer and also in the way they allow participants to benefit from the experiences of others through the sharing of useful tips, strategies and local information.*

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<sup>17</sup> Alzheimer's Australia (2016) Consumer Survey (unpublished).

<sup>18</sup> Alzheimer's Australia NSW consumer testimonials (unpublished).



*NDSP Revitalised: Report by Hall and Partner, 2015*

Carers have also highlighted: the positive impact of the information and education provided through the NDSP; the support in referrals and gaining access to specialist services; counselling and advice; social and therapeutic activities for the person with dementia; and establishment of social connections for themselves and the person with dementia.

Thus the redesigned dementia consumer support should continue to remain responsive to the need for joint services for the person with dementia and their carer, and preferably for the whole family. A separation across service delivery often does not work well for carers of people with dementia, which is why Dementia Australia has developed services that include both client groups, that is, people with dementia and their carers. This joint approach needs to be reflected in future iterations of the dementia consumer support services.

It is important that the redesigned dementia consumer supports continue to link carers to relevant, targeted education programs, such as those offered by Dementia Australia, to ensure their specific educational needs are met.



### **Question eight**

#### ***Is the proposed breakdown of funding proportions for each element appropriate?***

##### **Enhancing education and awareness**

While the significant economic and social impact of dementia has been recognised by the Australian Government with the 2012 decision to make dementia a National Health Priority Area, the lack of a fully funded dementia strategy has presented many barriers to realising action against this priority. The lack of such a coordinated response has many implications, including the acceleration in morbidity associated with dementia. Dementia is now the leading cause of death for women in Australia, and the second leading cause overall, with projections by the ABS estimating it will be the leading cause of death in Australia within the next 5 years.<sup>19</sup>

Emerging evidence has shown us that behavioural and related clinical risk factors are common risk factors for most chronic conditions. While there is increasing community awareness of the link between behavioural risk factors and physical health status, there is little awareness of the links between these behaviours and the risk of dementia. Therefore, in Dementia Australia's view, the redesigned consumer supports program should include an element of education around the modifiable risk factors of dementia, along with funding support to achieve progress against this crucial metric.

Research on trajectories of other chronic conditions such as diabetes, heart disease and stroke shows us that a greater focus at primary care level on risk reduction could reduce the number of people developing dementia, while timely diagnosis of dementia would facilitate the provision of early interventions that enable people diagnosed with dementia to live in the community for longer. Each year that a person can live in the community before being admitted to residential care offers significant savings to the health and aged care system as well as benefits for the individual's quality of life. However, any strategy to improve the engagement of the primary health care system with people with dementia and their carers needs to be developed in the context of a broader strategy on dementia. Thus, early intervention supports delivered through NDSP have, in the past, been curtailed by the lack of a targeted and national dementia strategy.

Despite these barriers, Dementia Australia has been able to leverage our expertise in the sector to build strong partnerships across service delivery, promoting education and awareness, as well as capacity development amongst important stakeholders and developing crucial resources such as:

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<sup>19</sup> Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online.



- Improving Timely Diagnosis by General Practitioners and Nurse Practitioners Project (working with DTSCs, RACGP, Australian Primary Health Care, the ANU and consulting broadly with professional and stakeholder groups in primary care);
- Making Flexible Respite a Reality Project (working with Carers Australia, care providers, consumers and the University of Wollongong);
- NQDCI projects with the Australian Dental Association; the Agency for Clinical Innovation (to improve allied health care), and NPS Medicines Wise.

This multidisciplinary capacity development approach has been important in creating broader service adoption. As the consultation paper recognises, many of the challenges faced by people living with dementia occur before they are considering, or would be eligible for, aged care services. While a dementia-specific information line and government-branded information website can be an effective part of the Information and Awareness elements of the redesigned services, these cannot be seen as an effective or sufficient strategy to deal with the lack of awareness of dementia and the services that can support consumers.

In Dementia Australia's opinion, besides an information and awareness focus, investment in a national programme to tackle the stigma and social isolation associated with dementia is also needed. So far, the focus of NDSP Information and Awareness funding has been to build awareness through targeted activities. However, we know that a larger scale, public health awareness campaign is more likely to deliver better outcomes that address the questions around poor reach of early intervention support for a chronic disease.

Providing strong community based support is also a much better strategy to deal with the overall prevalence of dementia and, in Dementia Australia's view, should be supported through a larger and more sustained funding pool that reflects the long-term savings this type of support can deliver. As such, the redesign of NDSP should include a focus on ensuring that services are linked to the larger objectives of a community support program. For example, effective early intervention and psychosocial support for people with dementia and their carers can increase quality of life, reduce stress and sometimes delay admission to residential care. Effective risk reduction and preventative health measures can delay the onset of dementia for up to five years, effective programs in the community and residential care can reduce unnecessary admissions to hospitals, and dementia focused programs in acute care can reduce length of hospital stays and associated expenditure.

Research released by Dementia Australia earlier this year also shows that programs aimed at raising awareness on the preventative and risk modifiable factors of dementia (such as Your Brain Matters) could aid in reducing the annual age-sex specific incidence rates for dementia in people aged 65 years and above by 5%. As a result, there would be nearly 36,400 fewer people with dementia in 2025 and almost 261,000 fewer people by



2056 compared with the current projections of the prevalence of dementia over the next 40 years. This alone could save more than \$120 billion by 2056.<sup>20</sup>

### Increasing envelope of funding

Dementia Australia notes the redesign and subsequent restructure of the funding components as outlined in the consultation paper. While this may represent an increase in funding across certain components of consumer support, the overall funding available to deliver services remains the same. But as demonstrated in our responses above, the need for community based dementia specialist consumer support is at an all-time high and funding does not – and will not – keep pace with demand.

A well-funded dementia consumer support program can also deliver large savings by providing support that prevents or delays hospitalisation in people living with dementia. For example, better access to primary care and community-based services has potential to reduce avoidable hospital admissions for people with dementia. People with dementia are major users of hospital services, largely due to the fact that dementia is a chronic health condition, which most commonly affects older people who are more likely to have other chronic conditions. People with dementia generally have a longer length of stay within a hospital than other patients, leading to greater costs to the health system.<sup>21</sup> There are several reasons that people with dementia may end up in hospital unnecessarily, including limited availability of appropriate care in an alternative setting (particularly respite care), little to no family support, lack of availability of medical services in the home, or a need for care whilst awaiting admission to another care facility. In NSW alone, the average cost of hospital care for people with dementia was generally higher than for people without dementia (\$7,720 compared with \$5,010 per episode). The total cost of hospital care for these patients was estimated to be \$462.9 million, of which around \$162.5 million may be associated with dementia.<sup>22</sup>

Whilst similar mainstream services exist in the community (e.g. counselling), given the complex and often changing nature of dementia, people affected by the condition need specialised knowledge and understanding that is not always available from more generalist services. The services provided under the redesigned consumer support therefore need to provide the following specialist services:

- Psycho-social support and counselling around the emotional impact of the dementia diagnosis; dealing with feelings of grief, loss, stress, anger; helping to resolve conflicts within families. Supporting carers including children to manage the

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<sup>20</sup> Ibid.

<sup>21</sup> Australian Institute of Health and Welfare (2013) *Dementia care in hospitals: costs and strategies*.

<sup>22</sup> Australian Institute of Health and Welfare (2013) *Dementia care in hospitals: costs and strategies*.



many and continuing changes to their daily lives, adjustment to new roles, managing behavioural changes, accessing external supports and care and then transitioning to residential care. This should include facilitating peer support options;

- Support and empower people with dementia to maximise their independence and participation at home and in the community;
- Support through one-to-one training, education or advice to assist with coping both post diagnosis and beyond, including; training for carers on communication strategies or managing challenging behaviours of a person with dementia; how to facilitate meaningful engagement for the person with dementia; supporting carers to maintain social networks; personal wellbeing plans and advance planning for the person with dementia and/or their carer;
- Advocate on behalf of the people with dementia or their carers with other service providers (this includes providing advice and support to other service providers to help them be more responsive to the needs of the person with dementia and their carer);
- Information provision to assist the individual and their family to understand dementia; to know about relevant services and how to access them; and,
- Support clients in the application for administration, guardianship, and advance care planning.

Dementia Australia remains concerned about the ability of the current funding envelope to provide these services to the more than 400,000 people living with dementia and their families and carers. We are particularly concerned about the consultation paper's lack of emphasis on the needs of carers of people living with dementia. Removing this focus from NDSP will result in a huge gap in the provision of much needed services for carers of people living with dementia that cannot be met by just mainstream support provision through the carer gateway as intended.

*“Absolutely vital. As a Carer, we think we can do it on our own, but suddenly I found myself overwhelmed with what was happening, and the opportunity to talk through the emotional drain dementia had on me as a Carer was therapeutic and allowed me to “move on”. Family and friends really didn’t understand what I was experiencing in my Carer role; they weren’t there 24/7. The Counselling Service both via the telephone and particularly face-to-face was extremely helpful, in assisting me resolve the many problems which emerge with dementia.”*

*Carer on the need for dementia specialist carer support*



In Dementia Australia's view, the redesigned suite of consumer supports should include services that meet the specialist needs of carers of people living with dementia and this should be appropriately funded through an increase in the program's budget.

## CONCLUSION

Overall, through this redesign process we should be looking at the impact that the NDSP program has on the lives of people with dementia, their carers and families. The redesign should focus on whether the program has met consumer needs, and evaluate the impact on communities and populations. NDSP should deliver outputs that reflect the growing need for dementia-specific services, but which also have some inbuilt flexibility to support the individualised needs of people with dementia, their carers and families.

DA believes that the redesign of consumer supports needs to take into consideration the following crucial issues:

- Increasing funding and resources to support further rollout of dementia consumer support in community to meet rising need.
- Strategies to further deliver more public information and build awareness on dementia, targeted towards risk reduction and public health approach of tackling prevalence.
- Targeted support for carers should continue in line with the views of carers and the evidence in the literature that supporting carers extends the period a person with dementia can remain living in the community.
- Services as part of consumer supports should be across the whole dementia continuum not necessarily focused primarily on early intervention.
- Further education and training, specifically targeting GPs is necessary, although the current funding envelope is insufficient to fund this outcome.
- There may be opportunities for greater use of remote technology for people in rural areas to maintain the flow of information and education, however it is also important to consider the need for a dedicated education program for existing health networks such as Aboriginal Community Controlled Health Organisations and other clinics that service remote and regional areas (especially in the NT) – use of remote technology alone won't work in these areas if local networks are not leveraged.

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, quality care for people with dementia within their communities is a vital. Consumer needs should thus remain paramount amongst all our considerations for this redesign. As was very eloquently stated by one of our consumers,

*“While finding a cure is at the top of my wish-list, ways to increase quality of life for people with the condition is equally important.”*



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*Trevor Crosby, person living with dementia.*

Dementia Australia trusts that the matters raised in this submission will be of assistance to the Department of Health in the further development of a holistic redesign of dementia consumer supports that ensure the best outcomes for all people living with dementia and carers.