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## Essential Dementia Consumer Supports

**Response to *Redesigning Dementia Consumer Supports*  
discussion paper for Ministerial Dementia Forum**

To:

**Ageing & Sector Support Branch  
Ageing & Aged Care Services Division  
Department of Health  
[dementia@health.gov.au](mailto:dementia@health.gov.au)**

*[www.anglicare.asn.au](http://www.anglicare.asn.au)*

## Anglicare Australia

Anglicare Australia is a network of 36 independent local, state, national and international organisations that are linked to the Anglican Church and are joined by values of service, innovation, leadership and the Christian faith that every individual has intrinsic value. Our services are delivered to one in 26 Australians, in partnership with them, the communities in which they live, and other like-minded organisations in those areas. In all, over 13,000 staff and 9,000 volunteers work with over 940,000 vulnerable Australians every year delivering diverse services, in every region of Australia.

In 2015/2016, six Anglicare Australia member organisations provided residential aged care for over 2,500 residents, and seven members provided home and respite care for 43,000 people in the community.

Anglicare Australia has as its Mission “to engage with all Australians to create communities of resilience, hope and justice”. Our first strategic goal charges us with reaching this by “influencing social and economic policy across Australia...informed by research and the practical experience of the Anglicare Australia network”.

## Contact Person

Roland Manderson  
Deputy Director  
Anglicare Australia  
PO Box 4093  
Ainslie ACT 2602  
T: 02 62301775  
roland.manderson@anglicare.asn.au

# Essential Dementia Consumer Supports

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This paper is a response to the questions posed in *Redesigning Dementia Consumer Supports*, the 2016 Ministerial Dementia Forum Discussion Paper, and represents the views expressed from members of Anglicare Australia, compiled on the network's behalf by Melbourne based aged care provider and Anglicare Australia member, Benetas.

For the purposes of the paper, it should be noted that the term consumer relates to people living with dementia and those closest to them who provide support.

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

The *relationships* that are forged with service providers afford a connection and a focal point for the individual with a diagnosis of dementia as well as their carer. This relationship is the key to ensuring that an individually centred and focused approach is the cornerstone of collaborative goal setting, care planning and evaluation. The long term impact is sustainable, measurable quality outcomes for consumers.

Some key touch points include

1. Time of diagnosis
2. Initial access to community based services
3. Transition to residential care
4. The person with advanced dementia and distressed behaviours
5. Episodes within the acute health system
6. End of life issues

### **Considering the current suite of available supports; which would you consider to have the greatest long-term impact, and why?**

Consumer supports that offer an awareness of the needs of the family unit are pivotal in achieving a positive long-term impact. However, the greatest long-term impacts are achieved with flexible and responsive models of care that are centred on being mindful of each individual's needs which change at different stages of the dementia journey. Adopting such a model would assist in reducing the risk for example for a person with dementia who lives alone with no connection to family.

Alzheimer's Australia is a constant for consumers, health practitioners, and providers and plays important roles at a national and a service delivery level. It offers counselling, information, education and training on all issues relating to dementia in the national and international sphere. As an industry peak body Alzheimer's Australia advocates and advises government on behalf of people living with dementia and those who support them.

## **Do you feel that there is equity for consumers in accessing services?**

Access to services can be viewed as being inequitable due to a number of factors. Primary access is now driven through the My Aged Care website, and within some communities there are many people who do not have the skills, support or equipment to access the internet. Face to face methods for sharing information remain an essential component of communication particularly when the language used to describe dementia in terms of diagnosis, stages, supports and information is frequently inconsistent, can be confusing for consumers and requires clarification.

Equity in access to services can be influenced by the (variable) skill and knowledge of those at the point of referral. A key area of potential inequity in access to service provision is within CALD groups that may not access services as they do not meet the cultural needs of the individual.

Additionally awareness of services is often relayed to individuals via carer support networks: the positive impact of such programs and services is often intangible and is not currently mapped or measured.

Dementia is up to five times more prevalent in Aboriginal people than in the general Australian population<sup>i</sup> (Smith et al 2008 as cited in Fyfe & Stafford 2016) and their unique cultural needs may not always be met or understood which can lead to withdrawal, depression, isolation and feelings of shame; impeding awareness of services or access to them.

## **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?**

To minimise crisis points, early connection with appropriate services is essential. If optimal outcomes are to be achieved, dementia support models must be developed and structured to meet the needs of individuals along their journey. For example, support models for individuals with advanced dementia are not suitable for those with early stages of dementia. Introduction of an inappropriate service model will have a negative impact on engagement, inhibiting sustainable support and resulting in refusal of services. In time, these responses lead to crisis points. On the other hand, crisis points can be minimised when appropriate person centred models of service are adopted.

At times of crisis, individuals with a diagnosis of dementia and their carers do not want the added stress of needing to access a new and unfamiliar service. An experience from the Case Study Bank of one of our member agencies describes a carers experience as 'the system just keeps letting us down'. Services should be developed that are flexible and responsive, offering a range of models of care within a familiar environment. A need to access new services at a time of crisis, often leads to exacerbation of symptoms and stress for both the individual and carer, and this concern may lead to refusal of services to minimise the longer negative impacts experienced by both the individual and carer.

A health crisis usually precipitates the necessity for hospitalisation and permanent residential placement. Triggers for what constitutes a deterioration in physical or cognitive health is often noticed by the primary carer yet not taken seriously among clinical professionals who adopt a 'wait

and see' approach. This can lead to an escalation of the issues for the person with dementia and feelings of frustration and a devaluing of their contribution for the carer.

Goals of care in dementia change over time, and when carers are informed about dementia and its progression changed care needs will be anticipated and managed. 'There should be no surprises for a carer especially as the person they are caring for nears the end of life'<sup>ii</sup>. Tolman and Morrissey provide a simple framework so that carers and clinicians are speaking the same language when discussing stages of domains of dementia; with a focus on managing the journey, palliation and maximising quality of life.

Improved consumer involvement, listening to and engaging with people who live with dementia and those who care for them decision making and all aspects of the journey will assist providers to become more agile in their service design.

Consumer access to respite services without long delays (weeks or months) in accessing these services will assist in preventing carer burnout.

The proposed new Integrated Plan for Carer Support Services (the Plan) seeks to provide an integrated support service with carers and the sector. It is hoped the efficacy of the Carer Gateway (stage one) reveals a positive uptake, and lessons learned will be incorporated into the second stage before being rolled out.

## 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?**

Ongoing communication regarding services and transitioning processes should be readily available to consumers in a number of formats. *My Aged Care* is only one forum for the dissemination of information, and not all carers find this user friendly.

The Alzheimer's Australia Key Worker Program (for people diagnosed with Younger Onset Dementia) is an example of how consumers can be assisted to navigate the interfaces of the health and aged care system. This model provides a connection and relationship point, where current and relevant awareness and knowledge can be shared and disseminated. Connection with Key Workers at the time of diagnosis, with access to this resource for the duration of their journey, is beneficial and provides a continuum for the individual and their carer.

Carers build relationships with other carers within carer support programs, but unfortunately they are often only able to access these programs for specific periods of time, or while the individual with dementia is within a specific program. To assist consumers to navigate the interface and transitions to other settings, they should be encouraged to continue with carer groups if they wish to. In-home respite and transport to and from support group meetings can make a big difference to accessing this service.

Ongoing carer support programs that are local and serviced based can provide a social connection point for the carer and within these forums, advocacy and education occurs through formal and peer sharing and learning. Service providers should be encouraged to deliver carer support programs where carers can remain for the period of their journey.

Build on the Key Worker model. Increase health professional awareness of the Key Worker model & referral process. Support service providers to provide advocate, education and support carer groups.

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

Strengthening a commitment to carer support programs is a cost effective framework for the support of carers as they manage the journey with a loved one with dementia.

Maintaining and improving appropriate and accessible respite options provides sustainability and community connections for the individual with dementia and their carer, and reduces or delays the need for more intense interventions and supports.

Appropriate funding within the residential care setting is essential to improve the consumer journey. The current Aged Care Funding Instrument (ACFI) does not adequately identify person-centred needs that are due to cognitive impairment. Funding for this area of service provision should be reassessed and to ensure individual goals and needs can be addressed and funding is based on reablement and maintaining personhood .

The establishment of a National Dementia Register<sup>iii</sup> was first proposed in 2013 as a means to collect quality data on outcomes, assessment, diagnosis and management of dementia. Benefits include linking consumers to appropriate services in their area; potential participation in research; ensuring clear pathways for diagnosis and follow up; review of consumer access to particular services; reminding non users of the availability of services.

#### Early diagnosis and support:

As GPs are often the first point of reference it is important that written information in a variety of languages is readily available in waiting rooms.

The use of GPCOG is a fast reliable tool to help GPs diagnose dementia and provides a wealth of information on the next steps for the GP and on consumer organisations to support the person and carers. GPs and Practice Nurses need to encourage consumers to seek support early, provide information on Alzheimer's Australia Carer Gateway services.

There is further scope for the Primary Health Networks (PHNs) piloting the Healthcare Homes to collaborate with consumers in care coordination.

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

Transition is an individual and personal journey, with difficulties experienced at a range of stages. It must therefore be flagged that once again that an individually focused approach is the key to optimal outcomes. With this in mind, some common difficult transition points are

1. The diagnostic process. This is often convoluted, complex and lengthy
2. Acceptance of a diagnosis of dementia for the person and those close to them
3. Rescinding a driving licence
4. Knowing where to start when looking for help
5. Initial access to community based services
6. Looking for an aged care residential service and navigating the paperwork & acronyms
7. Transition to residential care
8. Episodes within the acute health system

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

Carer support groups which are accessible, irrespective of the stage of the journey, are beneficial and provide a forum for information sharing. Service providers should be supported and encouraged to manage carer support groups at a local level across both community and residential aged care settings.

It would help to run national marketing campaigns on television and social media as well as advertisements in municipal buildings and public spaces regarding the National Dementia Strategy; with the aim of improving knowledge of dementia, addressing the stigma and guiding people looking for help.

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

Anglicare members support the national marketing strategies and face to face promotion of technologies to assist with monitoring, communication and accessing services.

The use of technologies launched by Alzheimer's Australia supports staff and people living with dementia. They are:

- The Educational Dementia Immersive Experience (EDIE) is a new virtual reality smartphone app that enables staff to view the world through the eyes of a person living with dementia. This is used in conjunction with facilitated discussion by an AA Educator.
- The Alzheimer's Australia's *Virtual Forest* uses gaming technology to create a sensory experience, using a large interactive screen, and is designed to immerse the user in a calm, peaceful and enjoyable virtual environment. It is designed for people living with dementia.

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

The majority of consumers have little or no prior experience with using the services, and that renders them vulnerable and at risk of not utilising the systems at all. Some individuals do not have internet access or may not be computer literate, and therefore accessing resources such as the My Aged Care website or the Carer Gateway is difficult. Phone services frequently have automated messages, can include lengthy delays or may redirect consumers to the wrong service.

People with dementia often struggle with the stigma of their disease, without needing to feel deficient in tasks that are promoted as easy to use. A range of varied access point options and mediums may provide improved access and support.

The availability of an advocate in the key worker role is an example of where support may be gained to assist consumers to navigate the system.

### **3.**

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

### **What level of effort should be allocated to consumer supports in the pre-dementia stages, noting resources will be limited?**

Consumer and community awareness is a key area for increasing health literacy in the field of dementia. A commitment to the National Dementia Strategy will support:

- a. Better knowledge about dementia
- b. Promotion of dementia friendly environments
- c. Improved accuracy and earlier diagnosis
- d. Earlier access to key support points
- e. Collaboration between decision makers
- f. Earlier access to health and dementia management strategies
- g. Decrease in stigmatisation of dementia within the community
- h. Development of services that are agile and meet the consumers' changing needs

An ongoing robust commitment is required to redesign the consumer support in the pre dementia stages.

### **What role should the redesigned consumer support program have in service capacity building versus delivery of information and services to consumers?**

The redesign of consumer support programs should essentially sit alongside service delivery models, with the capacity for services to be measured by evidence and outcome based justification.

The role of the redesigned consumer support program in regards to service capacity should be

1. To identify gaps in service delivery within specific regions & consumer groups and advocate for appropriate service model development.
2. Provide information and support programs to consumers
3. To be an advocate and referral source for individuals with a diagnosis of dementia and their carers

Coaching for consumers and carers in decision making needs to be considered. This would require trained healthcare professionals who are supportive but non directive. Stacey<sup>iv</sup> proposes an inter-professional approach to shared decision making in clinical practice. This approach considers the multiple needs of individuals and families who are seeking assistance from community and provider service organisations. Increasing numbers of people with complex issues, need and use services in different sectors. Despite examples of good practice, services can continue to provide segregated services for consumers, rather than integrated approaches to support. A high level of agility across all service sectors is required to ensure effective support.

The *My Health Record* enables permission of multiple healthcare providers to share information and support the consumer in collaborative decision making for the best possible care.

There is increasing evidence that a number of different chronic conditions are associated with the development of cognitive impairment and dementia.<sup>v</sup> In response, Alzheimer's Australia Victoria has developed the Dementia Chronic Conditions Series Toolkits to support formal and informal carers to provide better assistance to people with dementia and other chronic conditions.

Allied health professionals are well-positioned to make a positive difference to the lives of people living with dementia and their carers; however there is a general lack of understanding about what they offer.<sup>vi</sup> Exercise, environmental modifications, engaging people with meaningful activities and skills that address everyday activities can support quality of life outcomes for people with dementia.

The University of Tasmania's online course have developed a range of online education programs in response to a need to build capacity for dementia care. These courses have afforded educational opportunities for many who previously had no access to tertiary education particularly with the two free Massive Open Online Courses (MOOCs) Understanding Dementia and Preventing Dementia.

**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 to accessing services (e.g. people from diverse backgrounds or people who live alone)?**

A proactive approach to funding should be embraced, noting the cost of ensuring sustainability and optimal health outcomes for the individual with a diagnosis of dementia and their carer will lead to decreased demand on the acute health and aged care systems.

Cognitive Rehabilitation (CR) may have some merit. It focuses on addressing individual therapy goals, with strategies and practical techniques for learning new information, practice in maintaining attention, concentration and stress management. A UK trial found that immediately after the

intervention, participants showed improvements in self-rated performance and satisfaction with relation to goals they had set and were more satisfied with their memory performance; caregivers reported improvements in their social relationships<sup>vii</sup>. If pilot findings are confirmed this study will provide CR as a clinically and cost effective intervention for people with mild to moderate dementia.

The amalgamation of one national peak body to communicate between government and industry sectors would provide efficiencies in costs and consistency in education delivery and cross-promotion of new innovations.

As previously mentioned, service providers will need to be respectful and responsive to consumers so that the service fits the consumers' goals rather than the person having to fit in with whatever the service offers.

### **How realistic is a goal of national consistency of services across Australia? Are there certain service elements which are better delivered by community/local organisations rather than the national level?**

A national approach is essential and realistic if it incorporates an inbuilt ability for local and community specific service modelling. The needs of different communities vary, as has been identified within the Primary Health Network (PHN) modelling and approach, and this philosophy should also apply to the redesign of dementia community support models.

The case worker/key worker model – if adequately resourced – will provide solid support, access and referral point for individuals with dementia and their carers, and will be a positive service element for the dementia consumer support model.

To assist individuals with dementia and their carers to navigate the system there needs to be an awareness of appropriate support models and services within the health profession, and that will lead to increased referral rates and greater access for consumers.

Key health professionals, including General Practitioners, Practice Nurses, Discharge Nurses and emergency department staff would be examples of focal health professional groups who would be able to influence referral rates to case/key workers who are able to assist individuals navigate the system. These key personnel could be a strengthened and constructive service element of a redesigned dementia consumer support model.

The objectives mirror those of the UK National Dementia Strategy - a system where consumers:

- know where to go for help
- know what services they can expect
- seek help early for problems with memory
- are encouraged to seek help early
- get high-quality care and an equal quality of care, wherever they live
- are involved in decisions about their care.

**END**

## References

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