



**dementia  
australia™**

The new voice of Alzheimer's Australia

# **Evaluation of the Aged Care System Navigator Measure**

**A response from Dementia Australia**

**6 September 2019**

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## About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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# Response to the consultation on aged care system navigator models

Please see below, Dementia Australia's response to the online survey

## Section 1: System navigator models

1. Please comment on the strengths and weaknesses of the different system navigator models
  - Patient navigator models
  - Nurse/professional navigator models
  - Family navigator models
  - Peer navigator models
  - Village and hub models
  - Other aged care system navigator models.

A key strength of the nurse/professional navigator model is the use of trained nurses and allied health professionals to assist individuals with complex health conditions to navigate between the healthcare, hospital and community settings. In essence, high quality dementia care requires a person-centred approach, whereby a combination of supports are utilised to meet an individual's needs and wants for their care. Person-centred care for people with dementia is particularly important due to the complexity of their condition. Even when individuals are affected by the same type of dementia, the symptoms experienced vary and the nature of the condition changes as it progresses, which creates a unique set of needs for care. Implementing a person-centred care approach not only requires an understanding of what the approach means, but it requires a navigator that is aware of the supports available that could appropriately meet the health and psychosocial needs of an individual – this is a skill most likely to be achieved by trained health professionals.

However, even amongst health professionals, awareness and understanding of dementia can often vary due the lack of mandatory dementia education across aged care professionals. To ensure professionals are equipped with appropriate knowledge of dementia, Dementia Australia strongly recommends the inclusion of dementia specific skills in a navigator model.

A key strength of the family model is its focus on building relationships with the service user to aid the development of person-centred care plans. Central to the delivery of a person-centred approach is understanding the individual and their wishes and preferences for care – which can only be achieved by meaningful conversation with the individual with dementia, their family and carers. Similar to the professional navigators, the family model also provides face-to-face and outreach services to help people access timely, appropriate and individualised care. A key request of many people with dementia and their carers is a navigator service with a face-to-face delivery option where people can have a conversation about their care needs and the various care options available to best meet their needs. Following a diagnosis of dementia, individuals are often left feeling confused and unsure where to turn for support; they are in need of guidance on what support will match their

personal goals and care needs. Providing an in-person delivery option is also important to individuals with dementia who may have limited communication; face-to-face communication enables people with dementia to participate more fully in conversations about their own care.

Finally, elements of the peer navigator model may be beneficial for some individuals with dementia and their families, and could significantly add value to a professional navigator model. For example, individuals who have recently diagnosed with dementia are often looking for guidance on what happens next and what to expect throughout the dementia journey. They may find peer support a useful emotional and personable support. However, due to the variability and complexity of dementia care, peer support alone may not be sufficient to ensure that the highest quality care is delivered to each individual – person-centred care requires a holistic oversight of the health and aged care systems, which cannot be expected by all lay persons. In sum, peer-to-peer support may be a role best suited to work alongside a professional navigator, rather than in isolation.

## 2. Please comment on which system navigator models are most relevant to the Australian aged care context:

Dementia Australia recommends a navigator model that combines key features from the nurse/professional, family and peer navigator models. Firstly, the inclusion of health professionals to act as navigators provides some assurance that advice will be accurate and well informed (providing navigator staff receive dementia specific training). It is also essential that the navigator take a person-centred approach to developing care pathways. This requires a navigator with good oversight of the health, community and aged care services and supports which can meet the needs of each individual. The family model, and its focus on relationship building to deliver individualised care will be a key enabler to achieving a person-centred model, and should also be considered in the development of an aged care navigator measure. Finally, a peer support function – that sits within or alongside a professional navigator model – would aid the person-centred and personable approach to the navigator, where people with similar experiences can support others by sharing information on what to expect and how to prepare for the future.

## Section 2: Design Principles

*The following design principles have been identified through the literature and consultations with representatives from system navigator models in aged care and other sectors as important to future navigator models in the Australian aged care context.*

- *Clear scope of role and practice. Aged care system navigators should have a defined scope of practice with roles and responsibilities that are transparent and commensurate with the skills and experience of the navigator delivering the service including guidance on management of risk*
- *Defined target population. Aged care system navigator models should focus on defined target populations, and prioritise those who are who are vulnerable or are experiencing barriers to accessing information and care*
- *Quality workforce. Aged care system navigators should be an appropriately qualified, trained, and supported (e.g. with ongoing training and professional development) workforce*

- *Implementation resources. Aged care system navigator programs should include implementation resources/toolkits/guides to support consistent, high quality delivery of navigation services*
- *Flexibility and adaptability. Aged care system navigator models should be flexible, adaptable, and responsive to meet the needs of the service user and the required level of service intensity*
- *Integration. Aged care system navigator models should aim to integrate fragmented and disconnected systems of care, and draw on existing local efforts/supports/infrastructure*
- *Relationship-centred services. Aged care system navigator models should identify the context, needs and priorities of the service user, in order to provide a personalised navigation service. It should also recognise the importance and influence of the relationships that exist between the service user and others, including service providers*
- *Active participation. Aged care system navigation should enhance the capacity of service users (including individuals/carers/families) to be actively involved in navigating the aged care system*
- *Linkages and partnerships. Aged care system navigators should dedicate time to developing their knowledge of local services, building partnerships with other organisations and sectors, and performing promotional/integration activities*
- *Evaluation outcomes. Implementation of aged care navigator programs should include an evaluation framework to monitor outcomes for service users and inform future policy decisions*
- *Independence. Aged care system navigators should be independent from service providers, to foster the necessary trust and rapport required to reach people facing challenges when accessing and navigating aged care services*

### 3. Please discuss the importance of these design principles

#### **Integration of supports and services**

Following a diagnosis of dementia, many people report feeling confused about where to go for support or are unaware of support that is available to them – which often delays their access to crucial supports and services. Therefore, a key feature of the navigator model is its ability to bring together services and supports into one place, to enable faster access to the right supports at the right time.

#### **Flexibility and adaptability/ Relationship-centred services**

Unlike other chronic conditions, symptoms of dementia can vary hugely between people, and can depend on the type of dementia, severity of the dementia, age of the individual and other comorbidities. The variance in dementia symptoms means that dementia care planning cannot take a one-size fits all approach. Instead care planning needs to be person-centred and incorporate support that meet an individual's full spectrum of needs, from health, personal care, allied health and psychosocial supports. This is why a key feature of the navigator must be to consider the breadth of support options that would contribute to each individuals unique set of needs and preferences.

A diagnosis of dementia also significantly impacts the lives of family and close friends of a person with dementia. In many cases, people living with dementia will come to rely on the

assistance of their family and friends – with 92% of people living with dementia currently receiving support from an informal carer. Over time, the pressures of caring for someone living with dementia can put strain on the carers health and wellbeing. Therefore increasing access to carer supports should be considered in the development of an aged care system navigator. According to Dementia Australia advocates, carers need access to a range of supports that help maintain their health and mental health, in addition to educational supports to assist them in their caring role. The existing Carer Gateway aims to provide carers access to these supports, however we know from what our advocates tell us, the gateway is often underused. This may be because of carers not seeking out support, but it is also possible that carers lack awareness of the gateway and the services available to them. Combining access to the carer gateway into the aged care navigator would enable all those impacted by a diagnosis of dementia to receive the supports they need, when they need them.

### **Quality workforce**

Workforce is a critical enabler to the success of the aged care navigator, and workforce education must be considered as a key priority in the development of the navigator. Broadly, Dementia Australia views workforce education, including that of the aged care navigator staff, a critical priority due to the influence education has on the quality of care. Given the increasing prevalence of dementia, which is now estimated at around 447,000 people, it is reasonable to assume that people with dementia will contribute a large proportion of those accessing the aged care navigator. Therefore an understanding of dementia is clearly warranted, and will be critical to the workforce's ability to offer accurate advice on supports and services that may support the needs of an individual with dementia.

A concern often raised by our advocates is the lack of dementia awareness and education amongst the aged care workforce, including amongst My Aged Care staff. The lack of dementia awareness not only adds confusion to people attempting to access services, but it also delays access to support – which can have a knock on effect to the outcomes of the individuals health and wellbeing. Therefore, mandatory education on dementia and a person-centred approach to dementia-care, must feature as a key design principle.

### **Linkages and Partnerships**

People living with dementia from special needs groups, such as those from culturally and linguistically diverse backgrounds or Aboriginal and Torres Strait Islander people, often face additional barriers in accessing the aged care services they need. This is either due to language barriers, but also a lack of awareness from aged care staff around culture and understanding about what appropriate care looks like for different groups.

Taking a partnership approach, where the navigator works with local groups and community organisations would be an efficient method to improving access to those from different groups, and ensuring the navigator is equipped to support all individual, no matter their background.

### **Independence**

A key contributor to the complexity in accessing aged care supports is the lack of public transparency around providers including the services they deliver and their quality.

Progressively, those transparency issues have fostered a general lack of trust in providers,

and nervousness about who to select to provide their care. The aged care navigator needs to be attuned to the concerns of consumers, and consider an independent model that acts separately from service providers. An independent navigator would help assure people that the advice and guidance they are given is not driven by the competitive provider market, but by the needs of that individual and the supports that are available to them.

#### 4. Please list any other design principles you think are important/relevant to system navigator models in the Australian aged care context

The evaluation framework should consider ongoing awareness and marketing campaigns that consider how to engage other groups and new generations entering the aged care system. This includes individuals who may not have had previous exposure to aged care services and supports. Unlike the disability sector - which people can come into contact with at any age - many people will only interact with the aged care sector later in life, potentially following a diagnosis or through an older family member who needs support. The lack of preparation and awareness before entering aged care or interacting with aged care can often add to the confusion experienced upon entering the system.

Targeted marketing campaigns that look beyond people over 65, and those already in the system should be considered. This includes, engaging upcoming generational cohorts, and groups who may come into contact with the aged care system earlier than 65 - for example people diagnosed with younger onset dementia, who often rely on aged care supports, before the age of 65.

### Section 3: Components of system navigator models

#### 5. Please comment on which model of delivery is best suited for the system navigator

The delivery mode for the aged care navigator must consider the geographical spread of people who need to access services, the variability in access to technologies, and the variability in comprehension of technology use.

In addition to these variables, it is also important to consider the most appropriate methods to aid rapport, trust and relationship building – which is key to a person-centred approach.

People living with dementia often value access to a face-to-face service which allows them to have a conversation about their care needs and what supports are right for them and facilitates them developing a care plan that best suits their needs. A mixed approach is viable, whereby face-to-face delivery approach is achieved through an outreach or community hub style delivery approach.

Face-to-face or telephone services are also beneficial to people with dementia who have communication difficulties – a common symptom of dementia. For individuals with limited communication, written information and online systems are more difficult to navigate and comprehend, which subsequently limits the amount the individual can engage in discussions around their care. Alternately, face-to-face interaction enables people with dementia to engage and get across information so they can inform on their own care.

Therefore, to fully accommodate to the needs of people with dementia, Dementia Australia recommends a flexible mode of delivery, where a range of contact methods e.g. face to face, phone, email and skype are available.

6. Please list any other components you believe are important/relevant to system navigator models in the Australian aged care context

Dementia Australia were pleased to see consideration go to care planning, and the importance of developing care plans in consultation with the individual and the families or carers. Due to the progressive loss of cognitive capacity experienced by people with dementia, many individuals in the later stages of dementia may lose the ability to make informed decisions around their own care. Therefore to ensure that care reflects the wishes and preferences of people with dementia, advanced care planning, which involves family and carers, is considered good practice. A navigator that supports early care planning will ultimately support the long term care of people with dementia.

As dementia progresses, symptoms will likely change and increase in intensity. To support the increasing needs of people with dementia it is important that services can appropriately respond to the changes in need, so individuals always receive neither too high or insufficient levels of care. Dementia Australia supports a reablement approach to care, where individuals are encouraged to act as independently as possible, for as long as possible. Reablement approaches ensure that individuals make the most of their abilities, stay active and participate in meaningful activities. Adopting a reablement approach also reduces the sense of 'feeling helpless' – especially amongst people living with dementia, who experience a progressive loss in their abilities. Flexible care, that increases and decreases in intensity according to the individuals current need is central to a reablement approach – and Dementia Australia is pleased this has been considered a component of the navigator model.

The navigator needs to ensure the dyad - the person living with dementia, and their carer/family - are individually and collectively supported. Recent reforms have introduced greater emphasis on individual needs, which is important, but can impact on the ability for supports to respond to the collective needs of the person with dementia and their family/carer. As dementia progresses, carers and families experience increasing pressure, and can often feel overwhelmed as dementia symptoms become more severe. To prevent burnout or undue stress, families and carers must have access to supports which help them to maintain their own health and wellbeing, in addition to supports to assist them with informal caring duties. Therefore it is important that the navigator considers both the individual and collective support needs of the individuals impacted by a diagnosis of dementia.

## Section 4: Implementation of system navigator models

7. What do you consider the most critical barriers to the implementation of aged care system navigator models in Australia?

The barriers relating to capacity, reaching target population, funding and integration are the most critical barriers to overcome.



The capacity of the navigator workforce and their ability to appropriately accommodate the needs of people living with dementia, their carers and families will be central to the navigators success - which is why Dementia Australia strongly advocates for specialised navigators. Dementia Australia also agrees that defined and clear boundaries for the navigator role will be essential, this will also ensure the model is sustainable, from a workforce and funding perspective.

People living with dementia, their carers and families, are often unaware what supports and services are available to them, as would be the same for the navigator service. To reach the target population, the navigator role must be integrated into the diagnosis pathway and engage health professionals who are involved across any stage of dementia. In essence, the navigator needs to be automatically referred to by all health professionals, no matter what stage of an individual's diagnosis. The Scotland post diagnostic support model is a good example of this, and this model is achievable due to the government support of the model (financially and through legislation/policy).

Cultural and geographical diversity also needs to be considered in the implementation of the aged care navigator. Currently, individuals in remote areas, in addition to people from culturally and linguistically diverse backgrounds are at a disadvantage when it comes to accessing aged care systems. Therefore the aged care navigator needs to consider the various groups who currently have limited access to services, and consider strategies that best engage these groups. For example, local community hub models which provide an access point for those in rural communities.

#### 8. What are the most critical enablers to implementation of aged care system navigator models in Australia?

As mentioned previously, a key enabler of the aged care system navigator is marketing, and raising awareness to the navigator so all potential users clearly understand the purpose of the navigator and know how to access it. It is also important that people know to access the navigator at the point of a diagnosis, so supports can be in place in a timely manner.

GPs are often the first point of contact for people recently diagnosed with dementia, and it is important that they are aware of the navigator so they can direct people to services and supports immediately following a diagnosis. More broadly, the navigator model needs to be integrated into health pathways, and diagnostic pathways, as this will ensure the target population are reached and can access supports promptly following a diagnosis. Ultimately, early referral to a system navigator would significantly improve the timeliness of access to supports, and potentially improve outcomes of individuals with dementia, their carers and families.

To ensure the inclusion of remote, Aboriginal and Torres Strait Islander, and Culturally and Linguistically Diverse communities, the navigator should implement a partnership approach. Relationships and information sharing between local communities and organisations could support the delivery of the navigator, and ensure the navigator is delivering culturally sensitive and appropriate services from the outset.

Another substantial enabler is accessible, user-friendly technology. Following the introduction of the My Aged Care website, it received multiple criticisms over its design and the lack of key information on providers. Taking on board this feedback, it is important that

any technology that is created, be simplistic in design and contain clear and concise information. There also needs to be an easy to reach face-to-face outreach program or community hub option which all users are able to access.

#### 9. What other implementation considerations should be taken into account?

Younger Onset Dementia refers to any type of dementia that is diagnosed in someone under 65 years of age. Typically, people under 65 access support through the disability service (NDIS), however, due to the complexities of their condition, many disability supports are not equipped to support an individual with Younger Onset Dementia. Therefore many younger people rely on aged care supports - such as respite care and residential care. Despite the recognition that younger people can access aged care services, the lack of communication between the disability and aged care systems makes it particularly difficult for this group to access the supports they need. As a result, Dementia Australia spends a considerable amount of time advocating on behalf of people with Younger Onset Dementia to support them in accessing the right supports.

Younger people accessing aged care supports is becoming increasingly prevalent, especially amongst people with dementia. Therefore the aged care navigator needs to be attuned to the navigational issues experienced by this group. Mapping out the interdependencies between the aged care system and other navigators, such as the NDIS, will bring systems together so consumers can move more smoothly between systems, to reach the supports they need.