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**SUBMISSION IN RESPONSE TO THE AUSTRALIAN
GOVERNMENT DEPARTMENT OF SOCIAL
SERVICES CONSULTATION PAPER**

**DESIGNING THE NEW INTEGRATED
CARER SUPPORT SERVICE**

June 2016

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to respond to the Australian Government Department of Social Services consultation paper, *Designing the new integrated carer support service: A draft Service Concept for the delivery of interventions to improve outcomes for carers*.

Alzheimer's Australia applauds the Australian Government's recognition of the critical role of carers, and of the need to provide adequate support to carers. We welcome the development of a national strategy designed to improve outcomes for carers.

It is critical that the proposed Integrated Carer Support Service provides appropriate, high quality support for carers of people with dementia. Already, up to 1.2 million Australians are involved in caring for people with dementia in some way. With the ageing of the Australian population, we are likely to see a steep increase in the number of people with dementia, which has the potential to increase the demand for informal care for this group of people.

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 likely to be insufficient for many people with dementia as their condition advances, and additional informal care will be needed.

More than nine in ten people with dementia living in the community do so with informal carer support. However, there are 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.

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 structured interventions that combine information, education, skills training, and psychosocial therapies, led by qualified professionals, delivered over a period of time, and with active participation by carers, tend to show the most positive improvements in carer outcomes.

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 will not meet the needs of many carers of people with dementia.

Alzheimer's Australia services are recognised as effective and highly valuable in supporting carers, and our organisation brings immense experience and expertise to the provision of these evidenced-based services. It is critical that the new Integrated Carer Support Service takes a networked approach, linking carers to the specialised services offered by Alzheimer's Australia and other providers, to ensure that the needs of carers are met, and the capacity developed within specialised service providers is not lost.

RECOMMENDATIONS

1. The Integrated Carer Support Service should offer structured evidenced-based multi-faceted interventions combining information, education, skills training, and psychosocial therapies, led by qualified professionals, delivered over a sustained period of time, with active participation by carers.
2. Elements of carer support which currently lack strong research evidence but which are highly valued by carers, such as respite care and informal support groups, should be delivered through the Integrated Carer Support Service whilst at the same time further research should be undertaken to further establish the effectiveness of these approaches.
3. The implementation of the Integrated Carer Support Service should recognise that the needs of different groups of carers vary and that a one-size-fits-all approach will not be successful. The experience and expertise of existing service providers in delivering appropriate and specialised carer supports should be recognised and built upon, with the Integrated Carer Support Service taking a networked approach which directs carers to specialised supports appropriate to their needs.
4. It is critical that carer voices utilised to guide the development of the service. Particularly where the evidence base for interventions is currently inadequate, the expressed needs and preferences of carers should be paramount.
5. Case management through a “key worker” approach should be considered for consumers and carers from particularly vulnerable groups: for example, people with dementia and their carers from Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse backgrounds, and LGBTI consumers.
6. In addition to measures to facilitate access to respite care through care packages where this is available and affordable, the provision of respite care should be included as a key element of the Integrated Carer Support Service. For carers of people with dementia, the respite care service should include: a dementia supplement for all forms of respite care, in recognition of the higher costs of caring for a person with dementia; greater flexibility in the provision of respite care, to make respite care more responsive to consumer needs and preferences, including better funding to meet the high demand for centre-based day respite and in-home day respite; measures to reduce direct and indirect cost barriers to accessing respite care; and a co-ordinated approach that links respite with timely access for carers to counselling and support services

BACKGROUND

Dementia in Australia

Dementia is a complex chronic condition caused by one or more of a number of illnesses affecting the brain. It is a terminal condition that can impact a range of cognitive functioning including memory, language, and thinking.¹ It is cloaked in stigma and misunderstanding,² isolates people and their carers from social networks,³ and carries significant social and economic consequences.⁴

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 353,800 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia⁵. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050⁶.

While the onset of dementia is correlated with advancing age, the condition also affects some younger people. An estimated 25,100 Australians with dementia are under the age of 65. This number is expected to increase to 36,800 by 2050⁷. There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke, and frontotemporal dementia.

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum⁸. Dementia also has a profound social impact. People with dementia experience stigma and social isolation⁹, and family carers often find it difficult to balance work, life and caring responsibilities¹⁰.

As our population ages, and as more people survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men¹¹. The higher lifetime risk for women is mainly due to women's longer life expectancy.

The ageing of the Australian population, and the increasing numbers of people with dementia, will place unprecedented demands on both formal care systems and the provision of informal care.

¹ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529.

² George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

³ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁷ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

⁸ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁹ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

¹⁰ Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. (2015) Report for Alzheimer's Australia.

¹¹ Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al (2006). The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 37 (2):345-50; cited in Alzheimer's Association (USA) 2013 *Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf

The critical role of carers

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.¹²

The majority of people with dementia want to live at home for as long as possible, and the ability to do so is beneficial both for the person with dementia, and in terms of managing demand on the residential aged care system. People with dementia need access to quality formal care in the community, but the “informal” care provided by family members and other carers is also critical in enabling people with dementia to live well in the community for longer.

The vast majority of people with dementia living in the community (91%) rely on an informal carer to support them, and more than one in five (22%) rely solely on informal care and do not access any formal care services. There are a significant number of Australians providing informal unpaid care to people with dementia, and most of these are the spouse or adult child of the person with dementia.¹³ 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 14 hours per week of care. This is likely to be insufficient for many people with dementia as their condition advances, and additional informal care will be needed.

Carers make a significant economic contribution. It is estimated that the current cost of replacing family carers with paid carers would be \$5.5 billion per year. However, the sustainability of informal care is an issue of concern. While the number of people with dementia will continue to increase, there are concerns that the future availability of carers is under threat due to ageing of the population (already, half of all carers for people with dementia are aged over 65); workforce constraints; changing family structures; and a reluctance to provide informal care. It is estimated that by 2029 there will be a shortage of over 94,000 full time equivalent family carers.¹⁴

While the carer of a person with dementia may feel some positive impacts from the caring role, in many cases the impacts of caring can be extremely challenging. Caring for a person with dementia can lead to increased rates of stress, depression, and anxiety, as well as having a negative impact on the carer’s physical health. Caring can have a profound emotional impact, with carers reporting feelings of guilt, sadness, anger, lack of control, worry, and even grief. Caring for a person with dementia can also put carers at risk of social isolation; and often has significant negative financial impacts. The overall impact is greatest for carers who live with the person with dementia, as these people provide more hours of care on a day-to-day basis, and may experience disruption of their sleep due to night-time disturbances.¹⁵

¹² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹³ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, pp 7-8.

¹⁴ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, pp 7-8.

¹⁵ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, pp 9-12.

It is critical that effective supports are in place to provide carers with strategies and resources to cope with the demands of caring, as well as practical support and respite. Such supports will help to mitigate the negative impacts of caring, and increase carer well-being and the sustainability of the caring role. Indeed, the National Framework for Action on Dementia 2015-2019, agreed to by all governments across Australia, states that: “Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role.”¹⁶

Support provided by Alzheimer’s Australia for carers of people with dementia

Alzheimer’s Australia currently provides a range of supports for carers of people with dementia. Key elements of this support include:

- The National Dementia Helpline, through which consumers (people with dementia and their carers) have ready access to informed dementia specialists who can link them to information and support that is available both from national resources (such as the Alzheimer’s Australia website, My Aged Care and Carers Gateway) and services in their State or Territory. The Helpline is very well utilised and is often the first call for assistance in seeking advice, understanding symptoms, accessing a first line of counselling, progressing towards diagnosis and accessing post-diagnosis assistance and support. 64% of helpline callers are family carers with approximately 15,000 carers accessing the helpline per year.
- The Alzheimer’s Australia website, recognised as the most comprehensive collection of dementia information available in Australia in the recent KPMG review of dementia programmes.¹⁷ The website provides access to information including in the form of help sheets, and is very well utilised. In the last twelve months 3.17 million pages have been read on the Alzheimer’s Australia website. In addition PDF resource and fact files (including help sheets) on the Alzheimer’s Australia website have been downloaded 392,720 times. Information on the website is available in 43 languages, to support our culturally and linguistically diverse audience.
- Dementia awareness and information sessions, as well as awareness raising activities such as Dementia Awareness Month.
- Early intervention and ongoing services including the *Living with Dementia* series of education sessions; support groups for people with dementia and their carers; and counselling services. These services are in high demand around Australia.
- The Younger Onset Dementia Key Worker (YODKW) Program, a critical initiative in meeting the needs of people with younger onset dementia, who often “fall through the cracks” between the aged care and disability services sectors. Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice; and links people with services that are appropriate to their individual needs. This program was recognised as highly effective in the KPMG review.¹⁸ To date the program has assisted 1,586 people with younger onset dementia, and 1,866 carers.

¹⁶ National Framework for Action on Dementia, 2015-2019, p 14.

¹⁷ KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*.

¹⁸ KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*, p 18.

Alzheimer's Australia offices are located in communities in every State and Territory, providing support and education to consumers, workforce and service organisations, community organisations and local communities. Alzheimer's Australia combines national information and awareness raising with its ability to leverage local partnerships and local resources and provide local service provision. This also places Alzheimer's Australia well to improve support for hard to reach groups, including people living in regional, rural and remote Australia and special needs groups.

Alzheimer's Australia is committed to program delivery that is driven by and responds to consumer needs, underpinned by a commitment to evidence-based best practice and is locally responsive. A Quality Framework is in place and work continues at the national level to improve outcomes reporting, data collection and data integrity. Consumers are integral to program design, development and evaluation, and comprehensive structures are in place to support effective consumer engagement. Consumer feedback on the support services provided to carers by Alzheimer's Australia is overwhelmingly positive.

RESPONSE TO ISSUES RAISED IN THE CONSULTATION PAPER: DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE

The Draft Service Concept – overall comments

Alzheimer's Australia notes that the Draft Service Concept encompasses eight elements: awareness; information; intake; education; peer support; needs identification and planning; a multi-component intervention (carer mentoring, respite support, and financial support); and counselling.

Alzheimer's Australia is supportive of this comprehensive and multifaceted approach in supporting carers, and of the objective to ensure integration of the various components of the service. Programs that provide a number of interventions such as information, education, skills training, psychosocial therapies etc, generally over an extended period of time, tend to show significant improvements in carer outcomes, and are considered to be particularly promising.¹⁹

In identifying the needs of carers of people with dementia, Alzheimer's Australia has reviewed the research evidence indicating that structured multi-component and individualised psychoeducational and psychosocial interventions tend to show the most positive improvements in carer outcomes. Carers also express high satisfaction with other approaches such as case management, informal support groups, and respite care, but research evidence on these approaches to date is inconclusive.²⁰ Importantly, this does not mean that these approaches are ineffective and should be ruled out; it simply indicates that further high quality studies are needed in these areas.

While evidence for particular stand-alone interventions may be lacking, often these interventions in combination with others have been shown to be effective. Therefore, interventions should not be

¹⁹ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, p 14.

²⁰ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42.

ruled out simply because they are not effective on their own; they may be very valuable in combination with other interventions. The impact of the full suite of initiatives may be greater than the sum of its parts, and the impact of the integrated carer support service as a whole should therefore be assessed rather than relying on evaluation of single components.

Where research findings are inconclusive, it is critical that the views and preferences of carers themselves guide program development, while at the same time further research is undertaken. Where the views of carers themselves consistently support a particular intervention, it should be assumed that the intervention has positive benefits, unless and until it is proved otherwise.

The main focus of the Integrated Carer Support Service should be on direct care and support. Information and education is important, but people in need do not just want to know about services: they need to be able to access them. The current environment can often give an overload of information about services that sometimes the carer is not then able to access, due to supply and demand issues, eligibility criteria, or other reasons. This can be less than helpful. Support is particularly needed for strategies that encourage early intervention, peer support, and education.

There also needs to be a balance in the Integrated Carer Support Service between a preventative/early intervention focus, and support for those with higher levels of need and higher carer stress and impact. Support across this spectrum is vital.

Alzheimer's Australia welcomes acknowledgement that carers need support throughout the carer journey, but we suggest stronger emphasis needs to be placed on preparing carers for the time when they are no longer in a caring role. This needs to happen before, not during, their transition back to the workforce, and should include workforce skills development (career training), peer support and counselling.

It also needs to be recognised that most carers act as advocates for their loved one, either formally, as a substitute decision maker, or informally. The responsibility for medical decision making is increasingly falling on carers, many of whom who feel ill-equipped or under-informed (even with an advance care plan in place). The carer strategy needs recognise this emerging trend and provide carers with the appropriate support and information to perform the role of advocate and particularly of substitute decision-maker.

Alzheimer's Australia is strongly supportive of the inclusive approach that the Draft Service Concept adopts in its aim to be inclusive of carers from all backgrounds, including young carers, carers from CALD communities, Aboriginal and Torres Strait Islander carers, LGBTI carers, and carers from rural, regional, and remote settings. People with dementia and their carers from diverse backgrounds often have difficulty accessing mainstream services, and Alzheimer's Australia has developed a range of innovative service approaches to address the needs of these groups. The following quote from Alzheimer's Australia's consumer survey illustrates some of the challenges for a carer from a rural community:

"We live in a small rural community - the majority of services we need are provided by large organisations that are not based in our area or familiar with our area. Problems include - lack of flexibility in times of service delivery, insufficient local staff to accommodate holidays or sick leave, poor poor poor internal organisational communication, assumptions that the carer will fill in any gaps (eg paper work not done, changing times of appointments) and the assumption that we have nothing better to do than sit at home and wait for them."

Alzheimer's Australia also notes that the Integrated Carer Support Service will need to take into account a likely high level of disability amongst carers themselves, given that, as noted above, half of all carers for people with dementia are aged over 65. The service will need to recognise that carers themselves are not a homogenous group, and may have varying levels of abilities and disabilities. The service must be sufficiently flexible to respond to these varying levels of need.

Furthermore, the Integrated Carer Support Service should be responsive to the need for joint services for the person with dementia and their carer, and preferably for the whole family. There is potential in this proposed integrated system for services for people with dementia, and services for carers to be completely separated in areas of assessment and provision, via a Carer Gateway that is separate from the My Aged Care Gateway. This separation often does not work well for cares of people with dementia, and hence Alzheimer's 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 the services offered through the Integrated Carer Support Service. In addition to being integrated with the My Aged Care Gateway, the Integrated Carer Support Service also needs to be integrated with the National Disability Insurance Scheme, to meet the needs of carers who have responsibility for both an older person, and a younger person with a disability.

The Draft Service Concept points out that carers are often involved with a number of organisations to have their needs met, and implies that this is a problem. While a lack of co-ordination between service providers can be problematic, a choice of service providers can also be an advantage where different organisations offer different approaches and philosophies, and the consumer can select the service which is most appropriate to them. The implementation of the Integrated Carer Support Service should include consideration of maintaining such flexibility and choice.

Comments follow on each element of the Draft Service Concept.

Awareness

As noted in the Draft Service Concept, many carers fail to identify as carers, and are unaware of or fail to access available services. A broad approach to awareness-raising will be needed to tackle this issue. In the case of dementia, stigma is known to be a key factor delaying diagnosis and impeding access to services. Dementia has profound social implications for both people with dementia and their family and carers. Often after a diagnosis of dementia, people experience social isolation and discrimination²¹. Friends and even family members may stop visiting or calling because they feel unsure of how to interact with a person who has a cognitive impairment. Many Australians have little understanding of dementia and are unsure of how best to respond to people who are living with the disease²².

As a result, people with dementia and their carers often lead increasingly lonely and isolated lives, when with support they can remain actively engaged and connected with the community. This isolation can lead to mental health concerns including anxiety and depression and can exacerbate the symptoms associated with dementia. People with dementia who are isolated often require residential care services earlier. Carers who experience social isolation can have difficulties maintaining their caring role and experience negative impacts on their mental and physical health.

²¹ Alzheimer Society of Ireland (2012). *Report on creating dementia friendly communities*.

²² Alzheimer's Australia (2008). *Dementia symbol research project: 'getting dementia out of the closet'*.

In order to address these concerns, we need local programs that leverage community resources to raise awareness about dementia within the community and to improve access to opportunities for social engagement for people with dementia and their carers. International evidence suggests that dementia-friendly communities are a cost effective and successful solution with some countries including the United Kingdom and Japan adopting a 'Dementia Friends' program as part of the approach. The program aims to educate and train interested community members to recognise the signs and symptoms of dementia and effectively communicate with a person who has dementia.

Alzheimer's Australia has begun piloting dementia-friendly communities across Australia, based on successful overseas models. Experience from these pilots suggests that there is significant community and business goodwill that can be leveraged to better support people with dementia. Very small investments have led to significant achievements within Australian pilot communities.

Alzheimer's Australia has been advocating for the establishment of a national Dementia Friends program in Australia, building on and translating the successful Dementia Friends programs in the UK and Japan to be relevant for the Australian context. This program would offer dementia education sessions to interested members of the public, and businesses and other organisations. This program would be complemented by a National Dementia-Friendly Community Resource Hub, leveraging the success of the Australian pilot sites and work undertaken in a number of communities across Australia to provide information, resources, best-practice guides as well as opportunities for networking and support for creating local dementia-friendly communities.

We note that these proposals fall outside the scope of the proposed Integrated Carer Support Service. However, community led approaches such as this could leverage the work of the Integrated Carer Support Service. It should also be noted that this approach to raising awareness and identifying carers is targeted specifically to carers of people with dementia, illustrating that a "one-size-fits-all" approach is unlikely to work for all carers.

Information provision

While there is no clear evidence that information provision alone has a positive impact on caring for a person with dementia, there is evidence for the positive benefits of information provision in combination with other interventions such as skills training and telephone support²³.

To be of value, information must be relevant and targeted to the specific issues being faced by the carer. In the case of dementia, Alzheimer's Australia provides comprehensive dementia-specific information through the National Dementia Helpline, through the national website, and through library and other services offered by State/Territory offices. This information provision is linked in with other interventions such as education sessions, support groups, and counselling, reflecting best practice as indicated by research evidence.

²³ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, p 13.

Intake

It is noted that the objective of the “Intake” strategy is to connect carers to services and supports, particularly from national infrastructure, by collecting basic information.

The critical issue here will be to ensure that any national “intake” process for the Integrated Carer Support Service, which would apply to carers as a whole, does not delay their referral to specialized support services, nor duplicate the intake processes undertaken by these services.

The implementation of the MyAgedCare website has been disappointing for consumers who have found it difficult to use and call centre staff who are not sufficiently trained to understand the specialist needs of people with dementia. Consumers repeatedly indicate that they much prefer dealing with local people in a face to face setting. It is essential that any national intake process takes this feedback into account. Ideally there should be multiple entry points, including local services, which can provide access to the Carer Support Service. Carers are not turned away due to restrictive rules relating to entry points. A “no wrong door” approach should be taken, to ensure that intake processes always facilitate and never hinder access to services. The negative experiences of some consumers with regard to the My Aged Care portal illustrate the barriers which can emerge if entry points are not sufficiently consumer-friendly.

Education

A recent review of educational interventions for carers found a moderate effect on the impact of caring and a small effect on depression. Elements that increase effectiveness include active participation by carers, an individualized approach, and ongoing information. However, evidence is limited regarding a sustained effect over time.²⁴

While carers may be time poor and reluctant to complete education programs which are of marginal relevance, many carers highly value specialized education targeted to their specific issues and needs. Education was ranked third, after peer support and respite care, in a recent Alzheimer’s 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.²⁵

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, eg my husband has Fronto Temporal

²⁴ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, pp 13-14.

²⁵ Alzheimer’s Australia 2016 Consumer Survey (unpublished).

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.”²⁶

It is important that the future Integrated Carer Support Service links carers to relevant, targeted education programs, such as those offered by Alzheimer's Australia and other specialised services, to ensure their specific educational needs are met.

Peer support

Peer support programs tend to be more informal and less structured than other interventions, and the approach can vary significantly between programs and groups. Research into the effectiveness of support groups is limited. Available research indicates that support groups can improve carer satisfaction and subjective wellbeing; empower carers and produce a sense of competence in the role; foster the use of formal support services; and help carers to feel understood. However, there is no conclusive evidence for such groups reducing the negative impacts of caring, such as carer depression, and further research is needed.²⁷

The KPMG review of dementia services found that although there was much evidence of consumers and carers valuing current support service models involving support groups and peer support, a small number of stakeholders from dementia services, aged care providers and health services questioned the effectiveness of these services for people living in regional and rural areas. Some of these stakeholders also questioned the appeal of those delivery models to younger consumers and carers.²⁸

Despite these queries regarding the effectiveness of peer support, 25% of respondents to the Alzheimer's 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 knew, everything that came up. That was really really helpful and still today is helpful. I feel I really got all the

²⁶ Alzheimer's Australia NSW consumer testimonials (unpublished).

²⁷ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, pp 14-15.

²⁸ KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*, p 8.

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.”²⁹

The use of the 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 specialized provider.

Needs identification and planning

The objective of this component of the service is “to assist carers by identifying needs and providing aid in planning informal and formal supports”. This would appear to be somewhat akin to a case management approach. Case management to meet the needs of the person with dementia usually involves a professional who arranges and monitors a package of long term care services. A recent review found that case management may be effective in reducing the impact of caring and depression and in improving carers’ subjective well-being, but that there is a great variation in interventions, outcome measures, and reporting.³⁰

Involvement of carers in assessment of their own needs and preferences would be a welcome change to prevent the focus being largely on organisational views and preferences.

Greater resources need to be available to help carers plan ahead. Some carers feel so overwhelmed that they resist planning ahead, because it is seen as impossible. There needs to be greater support for people in this situation. It is also very important for carers to have emergency and contingency plans in place.

Alzheimer’s Australia would recommend that this element of the service focus not only on identifying needs, but identifying goals. Goal identification and planning, through a key worker approach, has been shown to be particularly effective in the case of people with younger onset dementia (onset before the age of 65). More than 25,000 Australians have younger onset dementia, and they face a unique set of circumstances compared to people who develop dementia in later life including different economic, family, workplace and social pressures. They can experience significant delays in diagnosis as dementia is often not considered as a likely diagnosis in a younger person. The majority of younger people with dementia live at home with their families. As the condition progresses, however, it can be difficult to access sufficient care services in the community to remain at home.

²⁹ 2016 Alzheimer’s Australia NDSP Evaluation Interviews (unpublished).

³⁰ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, p 14.

Alzheimer's Australia's Younger Onset Dementia Key Worker (YODKW) Program is a critical initiative in meeting the needs of people with younger onset dementia, who often "fall through the cracks" between the aged care and disability services sectors.

Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice; and links people with services that are appropriate to their individual needs. Eligibility includes being under 65 years on first contact to the program; and includes all forms of dementia, including a person with symptoms of dementia that have not yet been diagnosed. Key Workers co-ordinate service access across disability services, aged care services, and other services.

Individualised support through a key worker approach has been demonstrated to be highly valuable for people with younger onset dementia and their carers, and it is likely to be similarly valuable for other people with dementia and their carers, particularly those from diverse backgrounds (for example Aboriginal and Torres Strait Islander people, people from CALD communities, and LGBTI people). For carer services to be successful in the area of dementia, it would be beneficial to have a key worker role with dementia expertise involved.

A multi-component intervention (financial support, carer mentoring, respite support)

Multi-component interventions (programs that provide a number of interventions such as information, education, skills training, psychosocial therapies etc, usually over an extended period of time) tend to show significant improvements in carer outcomes, and are considered to be particularly promising.³¹

The proposed Integrated Carer Support Service as a whole could be seen as a multi-component intervention, so it may not be logical to group just three specific services (financial support, carer mentoring, and respite support) together under this heading – they may be better listed as distinct elements of the proposed service.

Alzheimer's Australia is broadly supportive of the proposal to provide financial support, carer mentoring, and respite support as part of the service. Our comments here will focus on respite support.

Respite support

The purpose of respite is to enable the person receiving care to continue to live at home in the community with a healthy, stress-free carer and to enable the living partnership to continue for as long as is appropriate. From the carer's perspective, respite is time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care. From the care recipient's perspective, respite is the participation in an enjoyable activity (or activities), that is meaningful and appropriate, that provides opportunities for social engagement, companionship and stimulation and which supports them to live in the community for as long as possible and which is delivered in a dignified and respectful way.³²

³¹ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, p 14.

³² Howe, A for Alzheimer's Australia (May 2013). *Respite review policy paper. Report prepared for the Department of Health and Ageing*. Alzheimer's Australia Numbered Publication 33, p 10.

Respite care plays a critical role in providing a break for carers as well as an important opportunity for social engagement for the person with dementia³³. Often respite is essential to ensuring that family members can continue caring for the person with dementia at home³⁴. Unfortunately there are few respite services that have services specifically designed to support people with dementia. In fact as care needs increase, people with dementia are often turned away from respite. Many respite services say that they are not staffed to provide care to people who have behavioural symptoms or who are incontinent.

Over half of co-resident primary carers of people with dementia have indicated they need more support, and the greatest single unmet area of demand is for respite care. Evidence of the effectiveness of respite care in improving carer outcomes is mixed, and use of respite care by carers of people with dementia is lower than would be expected. However, those who do use respite care report high levels of satisfaction, in terms of allowing them time for self-care and other important activities, and providing relief from the caring role. Some negative experiences have also been reported, relating to poor quality and/or inflexibility of some services. A recent review has concluded that the measurable benefits of respite care vary according to the differences between carers, people with dementia, services delivered, and types of research carried out to date.³⁵

Carers repeatedly identify good respite care as an important support for a sustainable caring relationship. In a recent Alzheimer's Australia consumer survey, respite care was ranked second only to peer support, amongst programs identified by carers as having been most useful to them. One respondent commented:

*"For nearly 6 years my 88 year old mum has been attending Rosemary House [run by Alzheimers Australia Qld] on the Gold Coast 2 days a week as well as accessing income services 4 hours each week. We are both very pleased. Mum has a safe place to go where people understand her condition and acknowledge her individuality while treating her with dignity. I'm convinced this socialising and engaging in activity has helped slow down the progress of her Alzheimer's as well as minimising her anxiety etc. We have no family that can share her care. With the support of the helpful team of carers there... I think I'm coping quite well with the demands that go with caring for someone with Alzheimer's."*³⁶

In the same consumer survey, limited respite care was identified as the top area of support that consumers felt needed to be addressed.

Current residential respite options are very limited, and not assisted by the fact that people seeking and waiting for permanent care are often utilising this respite, so therefore these services are often not being truly used to assist people to remain in their home. Access to residential respite care and inability to access this respite in a timely manner needs to be understood in this context.

³³ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*.

³⁴ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*.

³⁵ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, pp 15-16.

³⁶ Alzheimer's Australia 2016 Consumer Survey (unpublished).

In addition, people with dementia have great difficulty accessing any in-home, day centre, or overnight/residential options if there are behaviours of concern. The Integrated Carer Support Service needs to address this current gap, as carers in this situation are at high risk and greater need.

Greater investment in flexible respite options, including day respite, is needed. The ability to 'cash out' or access informal respite through friends and neighbours is important, particularly for rural and regional carers (for example, when a carer needs to arrange someone to be at home with the person with dementia while they attend an appointment in a metropolitan area).

There is a need for a dementia-supplement for respite providers, similar to the supplement which is provided within community care. This supplement should only be available to services who can show they have put in place strategies and training for caring for people with dementia. This supplement would acknowledge the additional costs associated with providing respite to this group and would create an incentive for providers to develop dementia-specific services.

A comprehensive review of respite care in Australia, undertaken by Alzheimer's Australia for the Australian Government, put forward a range of recommendations for respite care policy. These included (but were not limited to):

- The need for a dementia supplement for all forms of respite care, in recognition of the higher costs of caring for a person with dementia.
- The need for greater flexibility in the provision of respite care, to make respite care more responsive to consumer needs and preferences, including better funding to meet the high demand for centre-based day respite and in-home day respite.
- The need to reduce direct and indirect cost barriers to accessing respite care.
- The need for a more co-ordinated approach that links respite with timely access for carers to counselling and support services.³⁷

Alzheimer's Australia is strongly supportive of the intent of the proposed Integrated Carer Support Service to improve access to respite care.

Alzheimer's Australia notes the Draft Service Concept states: "Given the Government's significant investment in respite, the objective of this service in this context, is to provide carers with the advice and support needed to ensure its effectiveness". This advice and support would include respite planning; respite booking; and supporting the carer to overcome resistance on the part of the care recipient, and to teach techniques to cope with separation issues.

There is an underlying assumption here that consumers should be able to access the respite care they need, via care packages. Unfortunately, this is frequently not the case, as the needs of carers may not be adequately assessed, and/or there may be inadequate respite care available, or there may be cost barriers. Consideration needs to be given to the inclusion of planned respite care as a service available through the Integrated Carer Support Service, in addition to the provision of supports to access respite care through care packages.

³⁷ Howe, A for Alzheimer's Australia (May 2013). *Respite review policy paper. Report prepared for the Department of Health and Ageing*. Alzheimer's Australia Numbered Publication 33.

Counselling

Many carers find counselling services very important in meeting the challenges of caring. The following quote from the Alzheimer's Australia 2016 consumer survey comes from a woman caring for her husband who was diagnosed with younger onset dementia:

“Counselling was the most significant support I could have ever had. It was extraordinary to have that support at that time. Of all the services that we’ve had, that was the most crucial service and timely service that I have had. As a mother and a person who’s supporting a husband with dementia and also guiding children through that difficult period of being told about the dementia, it’s incredibly important to have that support. It was invaluable. I had maybe 6 sessions and I was very impressed by the very forthright and honest nature of the discussion. I felt it left me on a very positive and determined course to deal with the diagnosis and live life as well as we could.”³⁸

There is some evidence to suggest that CBT can improve carer burden and depression. Research indicates that “Cognitive Reframing”, a component of CBT which focuses on family carers’ negative thoughts about their relatives’ behavior and about their own performance in the caring role, may have a positive effect on carer anxiety, depression, and subjective stress.³⁹

Carer mentoring and counselling as part of the model needs to be conducted by personnel with appropriate training and expertise, especially when dealing with a complex and specialised area such as dementia. Generic services often do not have the level of expertise required.

The Draft Service Concept paper poses the question of whether counselling services could be delivered to a broader group of carers through telephone or online channels. There is some evidence to suggest that telephone counselling can reduce depressive symptoms for carers of people with dementia and that it meets important needs of the carer; however, more research is needed in this area.⁴⁰

Many carers in their feedback to Alzheimer’s Australia have expressed in principle support for interventions and counselling that can be accessed at home, and have recommended counselling programs delivered by telephone and Skype, as well as YouTube tutorials. On the other hand, the KPMG review of dementia services found general agreement by stakeholders that some form of face-to-face support was needed by the majority of people affected by dementia, especially in the earlier phases: “This was particularly emphasised by carers and consumers as well as some aged care providers. Current efforts of some programmes to provide remote service delivery have been met with variable reports of success by stakeholders.”⁴¹

This indicates that while telephone and online counselling may work for some carers, others will need face-to-face support. It is recommended that a range of options be offered so that carers can choose the supports that will work best for them.

³⁸ Alzheimer’s Australia 2016 Consumer Survey (unpublished).

³⁹ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, p 14.

⁴⁰ Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer’s Australia Numbered Publication 42, p 13.

⁴¹ KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*, p 8.

CONCLUSION

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, there will be an increase in demand for informal family care. Already it is estimated that up to 1.2 million Australians are supporting people with dementia in some way, and this support is vital in ensuring people with dementia can live well in the community for as long as possible.

However caring for a person with dementia can have many negative social, psychological, health and economic impacts on the carer, and support is vital if the critical role of informal carers is to be sustained into the future.

Alzheimer's Australia welcomes the comprehensive and multi-faceted approach outlined in the Draft Service Concept for the Integrated Carer Support Service. However, it is critical that in developing the service, the Australian Government recognises the importance of specialised support for dementia carers. Generalised approaches to education, counselling and other interventions will not meet the needs of many carers of people with dementia.

Alzheimer's Australia has for many years provided a range of services to support carers of people with dementia, and brings great expertise to providing these services. It is vital that the expertise of organisations such as ours is built on and utilised in the new Integrated Carer Support Service. The services should take a networked approach, linking carers in with the specialised supports already available, to ensure that the capacity developed within specialised service providers is not lost.

It is also critical that carer voices are heard and utilised to guide the development of the service. Particularly where the evidence base for interventions is poor, the expressed needs and preferences of carers should be paramount.

We trust that the matters raised in this submission will be of assistance to the Australian Government Department of Social Services, in the further development of the Integrated Carer Support Service.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.⁴²

Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care⁴³. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

⁴² Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

⁴³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.