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Disability, Employment & Carers  
Department of Social Services  
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Dear Mr Christian

**CONSULTATION ON DELIVERING AN INTEGRATED CARER SUPPORT SERVICE: A DRAFT MODEL FOR THE DELIVERY OF CARER SUPPORT SERVICES**

Alzheimer's Australia welcomes the opportunity to respond to the Australian Government Department of Social Services' consultation paper, *Delivering an integrated carer support service: A draft model for the delivery of carer support services*.

Alzheimer's Australia is disappointed to note that the proposed model has adhered to a generalist approach towards service delivery, which is unsuitable for the specialist needs of carers of people living with dementia.

As we have noted in our previous submission to the consultation *on Designing the new integrated carer support service*, it is critical that the proposed Integrated Carer Support Service provides appropriate, high quality support for carers of people living with dementia. Carers of people with dementia need specialised support services that 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 living with dementia.

Our submission to the design stage of this consultation made the following 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 and 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

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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 are 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 living with dementia and their carers from Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse backgrounds, and Lesbian, Gay, Bisexual, Transgender and Intersex consumers.
6. In addition to measures that 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 living with dementia, a 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 living with dementia; greater flexibility in the provision of respite care, to make respite care more responsive to consumer needs and preferences and 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.

However, we are disappointed to note that the proposed draft model fundamentally differs with our recommendations and suggestions on some key elements.

### **Fragmenting the needs of people living with dementia and carers of people with dementia**

When a person begins to experience the symptoms of dementia, their families and friends begin a new and difficult journey of their own. They have to try and cope with the emotional impact and implications of a diagnosis, come to terms with and manage the changes they see in their relative/partner/friend, provide emotional and practical help on a daily basis and make difficult decisions about treatment options, use of services, finances and long term care. Some may have work, children and other family commitments to cope with as well.

Thus it is vital that any Integrated Carer Support Service should be responsive to the need for joint services for the person living with dementia and their carer, and preferably for the whole family. Far from integrating services across the family or support unit, however, the proposed service delivery model rather fragments the way consumers will be able to seek and access services. There is the potential in the proposed integrated system for services for people living 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 (MAC) Gateway.

There are already many carers who are registered to access services in the aged care sector through MAC and it is unclear at this stage whether the new Carer Gateway aims to share this

information or instead create duplication of assessments and other processes. Separating the access points to services for people living with dementia and their carers will only add to the complexity of their service experience and create additional barriers to appropriate access for both people living with dementia and their carers.

As we have noted previously, Alzheimer's Australia has responded to carer and consumer feedback about the challenge of separate assessments/service delivery by developing services that include both client groups, that is, people living with dementia and their carers.

*"It was probably a year after diagnosis that my partner and I went to the Living with Dementia program. He found it a really fantastic experience ... very positive and really helpful. That's when he started to feel good about attending younger onset dementia cafes which we both are now enthusiastic about attending when we can. It's a good way to network and we've developed friendships ... it's been really helpful to have some friends that we can share experiences with, and ... not to feel so alone."*

*Carer of person with dementia, on integrated services*

### **Experiences with similar approaches: My Aged Care Gateway (MAC)**

Since the introduction of MAC – in particular, since the integration of Aged Care Assessment Teams into MAC in February 2016 – Alzheimer's Australia has identified a number of issues that appear to be negatively impacting on access to timely services and support for people living with dementia (and their carers). Evidence that service access has decreased under MAC is suggested by the reduction in referrals to all Alzheimer's Australia State and Territory organisations with the exception of Western Australia, where MAC is yet to be adopted as the sole assessment and referral source. New South Wales, for example, has seen Commonwealth Home Support Package (CHSP) referrals reduce by 46% over March to June 2016.

#### **Case Study: Carers of person living with dementia interactions with MAC**

Over a period of a few weeks, three separate carers commenced the process and were blocked at the MAC contact centre screening through advice that that they do not have sufficient needs to access CHSP services and are not approved for a Regional Assessment Service (RAS) assessment. One client was advised if they still wanted to access the support group they would need to pay for it privately, as they did not qualify for CHSP funded services.

When Alzheimer's Australia staff investigated this with MAC they were advised the client was '*not needy enough*' and so they could not have a RAS assessment. Even after Alzheimer's Australia staff explained that the carers support group was an entry level service for carers to reduce the risk of stress and breakdown of the caring role, to maintain wellbeing and to assist them with strategies for managing a person living with dementia, they were advised that unless the carer was experiencing carer stress and there was potentially an imminent breakdown of the caring role, they did not qualify for services.

From Alzheimer's Australia's perspective, the processes related to MAC's registration, assessment and referral can be lengthy and this is contributing to service access difficulties. Through consumer reports we already know they have encountered wait times as long as three months from their first contact with MAC. Given that people living with dementia and their carers tend to make contact with Alzheimer's Australia when their circumstances are deteriorating it is likely that delays of this magnitude are causing considerable distress and compounding the difficulties people face. Nothing in the proposed model outlines how the Carer Gateway proposes to counter the concerns consumers already face with the MAC Gateway.

### **Understanding the dementia carer cohort**

The Department of Health and Ageing funded the AIHW's *Dementia in Australia* (2012) report and found some startling statistics that the Government needs to consider as they develop Integrated Carer Support. In 2011, there were 298,000 people living with dementia in Australia, the majority of whom (70%) were living in the community supported by around 200,000 informal carers. About 9 in 10 people with dementia living in the community were receiving care from one or more carers and about two-thirds of these carers were women. Half of carers of people with dementia were 65 and over. Around 42% of main carers of a person with dementia were the spouse/partner and 44% were the son or daughter.

Clearly then, the care needs of people living with dementia in the community are met by a diverse group of people. The implementation of MAC and the challenges encountered have already raised concerns around many of these distinctions. Consumers are already facing issues in dealing with an online system and teasing out complex issues such as differentiating the client from the carer—is there one primary carer? Or are there multiple carers? What's the definition of carer in the context of dementia?

### **Reliance on digital dissemination of information**

We are also disappointed to note that the model will rely heavily on the digital dissemination of information as the preferred strategy to engage with carers, followed by phone calls. Opportunities for face to face engagement have been heavily restricted, with the additional caveat that face to face assessment and targeted financial support would be limited to people with a specific need or cultural sensitivity. This is an entirely inadequate approach to meet the unique needs of carers of people living with dementia, who need appropriate early and timely interventions delivered by qualified professionals.

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

*Carer of Person with Dementia on Specialist Counselling*

The model outlined in the consultation paper appears to overlook research to date, which suggests that structured, multi-component and individualised psychoeducational<sup>1</sup> and psychosocial interventions<sup>2</sup> led by qualified professionals tends to show the most positive improvements in carer outcomes for carers of people living with dementia. We had specifically noted in our previous submission that, while more evidence is required, there is a small evidence base (in addition to informal feedback from consumers and carers) to suggest that telephone counselling can reduce depressive symptoms for carers of people living with dementia and meets important needs of the carer. Carer mentoring and counselling as part of the model needs to be conducted face to face by personnel with appropriate training and expertise, especially when dealing with a complex and specialised area such as dementia.

With the roll out of the National Disability Insurance Scheme (NDIS), our consumers have already reported significant issues, especially around the reliance on using non-face-to-face methods to discuss care planning and support discussions.

#### **Case Study: NDIS planning over the phone**

A carer received a call from an NDIS planner over the phone while she was at work and was asked if now was a good time to talk. The carer responded no and asked them to call back in 15 minutes when she could go to her car and talk more privately. The carer was unsure what the conversation would entail as it wasn't explained to her in detail. The carer then engaged in a conversation with the planner in her car and discussed her husband's needs for reasonable and necessary support with the planner. She mentioned to the planner that she works full-time and relies heavily on her daughter for support.

The carer then received the plan from NDIS a few days later with appalling implications. The carer will no longer be able to work full-time to support her and her husband financially. As a consequence of receiving this plan, the carer has now taken carer's leave until the end of the school term to care for her husband and work out how she will be supporting her family in the coming year.

The carer and her Alzheimer's Australia Key Worker have lodged an appeal with NDIS (application for review of a reviewable decision) and are now awaiting information regarding the review outcome.

#### **Fee for service model**

It is also concerning to note that the proposed National Education Initiative and National Counselling Program are all intended for delivery under a fee for service model, based on the 'certainty of demand forecast.' This would seem to contradict the broader move towards consumer directed care that we are seeing in aged care. The implementation of consumer directed care across Community Home Support Packages in aged care has already shown that, when faced with

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1 Psychoeducational interventions refer to interventions that include elements of education, skills training, information and advice about available services and resources, and require active participation by carers.

2 Psychosocial interventions refer to interventions that focus on identifying and modifying carer's beliefs and developing new strategies to help cope with caring demands.

limited budgets and high provider levied administrative costs, consumers tend to choose direct care services as opposed to education and counselling support services which are seen as more discretionary. The loss of these vital support services then ends up having an adverse impact in the long term and ultimately may increase the need for formal supports. We have already seen the unfortunate impact of trying to address the needs of our cohort of clients through a broad stream, fee for service approach, as has ensued since the roll out of the NDIS.

### **Dementia specialist knowledge**

Alzheimer's Australia also have reservations about the proposed move to a regional hub model that is staffed by people with basic qualifications (e.g. Certificate III in Disability, Community Care, etc.) and relevant experience. A Certificate III is a completely inadequate level of qualification for personnel who are expected to assess and meet the complex and unique needs of people living with dementia and their carers.

#### **Case Study: Impact of lack of dementia specialist knowledge**

The rate of progression of dementia in younger onset dementia can be very rapid and the current waiting periods through NDIS are a huge issue for clients of the Younger Onset Dementia Key Worker Program (YODKWP). In one unfortunate situation, a YODKWP client's condition deteriorated rapidly while he was waiting for appropriate support through NDIS. The client required hospitalisation and needed permanent placement, but there was confusion around who would support this process: the NDIS (who don't typically have capacity to find permanent placement) or the aged care system. The feedback from the wife of this client was that NDIS had no understanding of younger onset dementia and this hampered management of the situation. The client died while waiting for placement.

Indeed, we have heard of many challenges faced by people with YOD and their carers in the NDIS system, which stem from a lack of specialist knowledge of dementia. For instance, NDIS rules state that a client's plan must use 10 Medicare Benefits Schedule-funded GP psychological counselling sessions before allowing access to any specialised counselling support. For people living with dementia, we know that generalist psychologists, who have limited to no dementia knowledge, can only provide a small level of support. Even if clients do work through the 10 general sessions and ultimately get access to specialised dementia counselling, they lose valuable time and energy in that process.

As we have detailed through several submission to the Department, people living with dementia have unique needs and it is essential that they have access to specialised dementia services which cannot be delivered by the mainstream disability, aged care, mental health sector, or even by the Local Area Coordinators proposed under the NDIS.

### **Disrupting existing, effective network of dementia specialist services**

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.

As noted in our previous submission, Alzheimer's Australia delivers a range of critical supports for carers of people living with dementia. Key elements of this support include:

- The National Dementia Helpline, through which consumers (people living 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, MAC 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.<sup>3</sup> 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, which reach thousands of community members and promote the importance of timely supports.
- Early intervention and ongoing services including the *Living with Dementia* education sessions, support groups for people living with dementia and their carers and counselling services. These services are in high demand around Australia.
- The Younger Onset Dementia Key Worker Program (YODKWP), 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.<sup>4</sup> To date the program has assisted 1,586 people living with younger onset dementia and 1,866 carers.

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 an ability to leverage local partnerships and local resources and provide local service provision. This also positions Alzheimer's Australia well to improve support for hard to

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<sup>3</sup> KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report.*

<sup>4</sup> KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*, p 18.

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, is locally responsive and underpinned by a commitment to evidence-based best practice. 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.

We would thus urge the department to consider a dementia specialist approach across all levels of engagement with carers of people with dementia, and leverage the existing infrastructure in place through our organisation.

## **CONCLUSION**

The proposed model of Carer Support poses a real risk for people living with dementia and their carers. Redirecting funding and channelling it to multidisciplinary service providers who can cover ageing, disability and mental health will result in a breakdown of the more specialist provision that our cohort needs.

If we are to achieve a care system that supports people to live in the community for as long as possible, then carers are an essential part of the equation. Most people living with dementia rely on informal carers to supplement formal care; often the hours available even at the highest level of home care package are simply not sufficient to support a person living with dementia to stay at home. In order to provide people with choice over where they receive care, there is a need not only for a good system of home care but also for a comprehensive, evidenced-based approach to supporting informal carers of people with dementia.

Thank you for your consideration of these important issues. We would welcome further discussion with you.

Yours sincerely



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