



**Submission to the Department of Health
Consultation Paper:**

Specialist Dementia Care Units

19 January 2018

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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INTRODUCTION

Carers Australia welcomes the opportunity to respond to the Department of Health's Consultation Paper on "*Specialist Dementia Care Units*".

While we do have some expertise and experience in the area of dementia and its impact on carers, there are many issues and questions raised in the Consultation Paper which we are not in a position to respond to. In particular, we are not well placed to comment authoritatively on:

- issues that require clinical expertise
- the adequacy of the proposed funding and whether it could be better invested in other interventions
- the estimated demand for SDCU services.

In November 2017, Carers Australia made a submission to the Department of Health's Consultation Paper on the "*Redesign of Dementia Consumer Supports*". We hope that this submission is also considered in terms of the broader policy context in which Special Dementia Care Units (SDCUs) would operate.

We acknowledge both the benefits of these specialist units and the desirability of creating an alternative for people with very severe BPSD to acute care in hospitals or acute mental health facilities.

Carers Australia appreciates the national approach of the SDCU program, where roles and responsibilities of the Australian Government and the states and territories are clearly defined to facilitate the effectiveness and efficiency of service delivery to the targeted population, and which will help to address gaps and to improve equity of access to services across Australia.

We also particularly like the fact that there is flexibility around the SDCU model, where patients have the opportunity to transition to less intensive care settings, or possibly back into mainstream community, once symptoms have stabilised.

While Carers Australia supports the proposed SDCU model there are a number of issues and concerns identified in this submission that should be addressed.

THE SIGNIFICANCE OF THE PROPOSED SDCU MODEL TO CARERS

Caring for, and about, someone with dementia is generally a grueling, exhausting and emotionally draining experience.

Even if the person they care for has gone into a residential facility because they can no longer be cared for at home, family and friend carers experience grief, loss and guilt. They also experience anger, especially if they feel that their role as partners in care is not taken into

account (as is their right under the Carer Recognition Act, 2010) and if they perceive that their family member or friend with dementia is not being cared for adequately.

Caring for someone with dementia at home is recognised as one of the most challenging and debilitating caring roles. Carers of people with dementia not only provide more hours of care on average than most other categories of carers, but they are also more likely to experience significant strain, stress and psychological illness, such as clinical depression.¹ These carers are also at great risk of social isolation, as they may not participate in activities with family and friends.

In cases where the person they are caring for progresses from moderate to severe BPSD, especially where this involves aggressive behaviours, many carers make the decision that they can no longer care for the person at home.

However, this is not always the case. Indeed, some carers experience so much fear and guilt about placing someone they have loved and cared for over the years into residential care, that they will continue caring at home even in very dire circumstances – with potentially serious consequences for both themselves and the person with care needs.

“I wasn’t thinking about doing myself in or him in every day...I might have thought about it once every six months or something, what’s a way out of this ... You get to a point I suppose, you’re so drained, you’re so tired, you don’t want to let go of him, you don’t want to put him into a nursing home and you’re thinking now the best thing I could do for him is to bump him off and I’ll go with him and then we’ll go together.”

Interview participant for study by Siobhan T. O’Dwyer, Wendy Moyle, Tara Taylor, Jennifer Creese and Melanie J. Zimmer-Gembeck, *Homicidal ideation in family carers of people with dementia*, *Aging & Mental Health*, 2015, <http://dx.doi.org/10.1080/13607863.2015.1065793>

Many carers reach a point of desperation and despair because they are unaware that the behavioural and psychological symptoms associated with severe BPSD can be treated and reversed. Indeed they can only envisage them getting worse.

¹ Alzheimer’s Australia (2015) Caring for someone with dementia: The economic, social, and health impacts and evidence based supports for carers - Paper 42 October 2015, URL: <https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-42.pdf>

“It’s not like having a person with measles or something, because you know that they’re going to get better. But with dementia ... you know they’re not going to get better, they’re going to get worse and the caring becomes such an overwhelming ... not just the caring, it’s all the other issues, the financial issues, the emotional issues for you ... it is just the most debilitating, mind-crushing, hideous way to be, to live this life as a carer.”

Interview participant for study by Siobhan T. O’Dwyer, Wendy Moyle, Tara Taylor, Jennifer Creese and Melanie J. Zimmer-Gembeck, *Homicidal ideation in family carers of people with dementia*, *Aging & Mental Health*, 2015, <http://dx.doi.org/10.1080/13607863.2015.1065793>

It is also the case that, without them necessarily being aware of it, carers’ own inability to cope with or understand the manifestations of severe BPSD can trigger a deterioration in the condition of the person they care for, including aggression.

“The carer’s own characteristics, independent of dementia severity or other patient factors, can contribute to the development of aggressiveness. Carer responses to BPSD vary, and how carers accept their situation and manage dementia-related problems can influence the course of BPSD. This may be why, even when families receive professional support, two-thirds indicate an unmet need associated with how to deal with BPSD. A Cochrane review concerning the management of challenging behaviour in dementia noted that all eleven studies of effective interventions with family carers involved various psychotherapeutic or counselling approaches directed at the carer.”²

We understand, of course, that carers can access earlier interventions through DBMAS, which may help address the issues. However, when the behaviour of the person being cared for has deteriorated to the point where a more intensive intervention is required, the SDCU step up/step down approach is likely to provide a more effective solution, whether the person with dementia returns to the home (which many carers would welcome) or to mainstream residential aged care.

² Alexandra Feast, Martin Orrell, Georgina Charlesworth, Nina Melunsky, Fiona Poland and Esme Moniz-Cook, *Behavioural and psychological symptoms of dementia and the challenges for family carers: systematic review*, *British Journal of Psychiatry*, 2016 May, 208 (5)

ELEMENTS OF THE MODEL THAT WE SUPPORT

In general, we endorse the individual benefits (including to family and friend carers), the service level benefits and the systemic benefits identified on pages 25 to 26. We also endorse most elements of the model of care, particularly the step-up/step down approach.

We welcome that:

- carers will be involved in referrals and assessments which will generally be conducted face-to-face in the person's care setting
- family and friend carers will be engaged in care planning and delivery, to be accompanied by carer education and support
- the suggestion that evaluation elements would include family and friend carers.

ELEMENTS OF THE MODEL THAT CAUSE US SOME CONCERN

The location and geographical spread of SDCUs

We understand that catering to such a small subset of the population of people with dementia, given the costs associated with SDCUs, presents real challenges for determining the distribution of these units.

As acknowledged in the Consultation Paper:

“There are particular barriers to establishing SDCUs in non-metropolitan areas, including higher costs, longer travel distances particularly for families and carers, workforce limitations, lack of access to specialists and capital infrastructure investment.”³

The current Government commitment to establish at least one SDCU per Primary Health Network needs to take into account the accessibility of SDCU locations where the Primary Health Network covers a broad geographical region.

Carers Western Australia recommends that there be one SDCU or partnership and support (hub and spoke) for a partner organisation (e.g. Multi-Purpose Services) per 1-2 Health Regions, rather than per PHN. It is noted that telehealth is not mentioned as a way of staff with expertise sharing information with staff in remote areas with less exposure to people with very severe BPSD. This could also be utilised as a method of families and carers being able

³ Department of Health, *Consultation Paper on Specialist Dementia Care Units*, November 2017, p.42

to connect with the person they support without travelling to the location, even if they reside locally. Most Community Resource Centres (in WA) and Public Health Locations have the technology to use telehealth via video link.

Similar arrangements should be explored with respect to other states and territories.

We also note that one element of the program might be assistance for family and friend carers to visit the SDCUs.

Assessment arrangements

While we agree that ideally General Practitioners should have role in referral and assessment processes, we do not agree that GPs be considered or singled out over and above other opinion and assessment. As remarked in the Department of Health Consultation Paper on *the Redesign of Dementia Consumer Supports*⁴, there is a low level of dementia literacy among health professionals, and many GPs will have little expertise in relation to BPSD. There is some risk that over-emphasising or mandating the role of GPs could lead to poor quality assessment and bottlenecks in assessment processes.

Imposition of maximum limits on SDCU residency

We are not sure of the rationale behind the suggestion that each bed is generally expected to be occupied for up to 12 months at a time. If the clinical expert opinion is that if sufficient improvement will not be achievable for these patients if it has not occurred in a 12 month period, then the limitation seems reasonable in the interests of making efficient use of a valuable and limited resource. However, we note that a time limitation is likely to place stress on carers if it falls to them to find alternative accommodation at the end of the period or make a decision on whether they wish to continue providing care in the home.

The impact on the quality of care provided in residential aged care facilities

Given existing workforce shortages in this area, we have concerns that appropriately trained, skilled staff who exhibit a vocation to work in such a challenging area will be drawn into the SDCUs (with presumably improved training opportunities and career paths), leaving an even greater shortage of skilled staff in residential aged care settings. This, in turn, may exacerbate the progression of people in residential care from moderate BPSD or the lower end of severe BPSD to a level which will require transition to an SDCU.

We note that such workforce shortages are not confined to providing dementia care and are, in fact, endemic to the aged and disability care sectors. However, whether or not the SDCU proposal goes ahead, there needs to be more investment in dementia training, accompanied by better wages and conditions, to attract employees to this kind of work.

⁴ Department of Health, Consultation Paper on the *Redesign of Dementia Consumer Supports*, October 2017,

The impact of transitioning between care environments

Carers Australia understands that the SDCU model has been developed with the intention that patients with very severe BPSD who are in an SDCU unit would eventually transition back into home or residential aged care, after symptoms have stabilised. Transitioning to different environments can be very destabilising for patients and we are unsure that the benefits of SDCU occupancy will be sustained upon transfer, especially if the extensive supports and allied services that would be provided in the SDCUs are lost through transition to a lower level of services. Hence, measures need to be put in place to ensure a smooth transition back to residential care or, potentially, the community. In particular, time and resources must be made available to ensure that residential aged care staff and family and carers are equipped and supported to manage behaviour into the future