



**Submission to the Royal Commission into Aged  
Care Quality and Safety: Carers need a place to  
call home within aged care**

**30 July 2020**

**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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# Carers Australia Submission to the Royal Commission into Aged Care Quality and Safety

## Carers need a place to call home within aged care

### Introduction

The evidence given to the Royal Commission into Aged Care Quality and Safety (henceforth referred to as Royal Commission) by carers and the organisations which represent them, experts on aged care and carer supports, and research commissioned by the Commission all attest to the importance of carers being able to access supports through the aged care system to meet their own needs and to enable them to sustain care.

That evidence has also made it clear that the current mechanisms and funding to enable carers to access these supports are poorly focussed, fractured, derivative of the assistance offered to those they care for, often very hard to access and, in many cases, underfunded – as will be apparent from the commentary below.

This fracturing and downgrading of supports to family and friend carers of the aged has been occurring since *the Living Longer, Living Better* aged care reforms were introduced in 2013. It has in large part been the outcome of supports for carers being treated as a by-product of the supports for those they care for. With the introduction of consumer-directed care, there has been a significant loss of focus on carers' needs in their own right within the aged care system.

This is despite the fact that it is universally acknowledged that government funding of the aged care system would be unaffordable and unsustainable without the unpaid contribution which family and friend carers make to the capacity of older people to age at home, often at a cost to their own livelihood and wellbeing.

Among the supports advocated by witnesses was the need for carer education across a range of issues which they must deal with in their caring role, some of which can be found through the Carer Gateway. But access to respite has emerged as a particular problem, illustrated most poignantly by carer witnesses to the Mildura hearing. It is a problem that needs urgent action.

Not all supports formerly offered to carers of the aged have been replaced through the introduction of the Carer Gateway. While emergency respite can be brokered through the Gateway – providing it can be found – planned respite is only available through Carer

Directed Financial Packages whereby each eligible carer is entitled to up to \$3,000 (over a 12-month period). These packages are available to all carers, not just carers of the aged, and may be used for variety of purposes until the allocation for them runs out. Packages can be used for planned respite, but \$3000, especially to pay for overnight or weekend care, doesn't go far. We also note that forms of respite popular with some carers – such as community outings and retreats – are no longer available under the Carer Gateway funding.

The problems which have arisen with respect to respite and potential solutions have been amply conveyed throughout the Commission's hearings and in submissions. The comments below summarise these.

## Current Problems

### Access to Residential Respite

In 2018 Carers Australia conducted a national survey of organisations that helped carers to access respite services in residential aged care. Across Australia, 74% of respondents reported high or very high demand for emergency respite, while the level of high demand for pre-planned respite accommodation was 88%. Nearly 70% reported that both emergency and pre-planned respite were difficult or very difficult to access. Despite undertaking often exhaustive efforts to identify respite opportunities, 35% of respondents said they were only able to find respite beds some of the time.

Subsequently, as a result of a recommendation of the Legislated Review of Aged Care in 2017, the Aged Care Financing Authority (ACFA) undertook its own review of respite in 2018. The report noted that, while there was growing uptake of respite places in residential aged care, this reflected in part a market demand for the use of residential respite other than for the purposes of supporting carers and those they care for to remain at home as long as possible. This growing use of "respite" serves to give potential permanent residents an opportunity to "try before you buy" before making the commitment to become permanent residents of an aged care home. This undermines the intent and use of residential respite.

There are strong incentives for residential aged care providers to use respite beds with the expectation of gaining a permanent resident, as opposed to taking on short-term placements. The administrative requirements and costs of taking in a new resident for respite are high, and the subsidies are very low compared to those attached to permanent residents. In addition, respite funding does not address accommodation costs.

It can also be a challenge to manage respite in-take within the quotas imposed by the Aged Care Approval Rounds (ACARs) which determine the subsidisation for respite placements. Put simply, if a service goes over their approved quota, they won't receive the subsidy.

The Aged Care Financing Authority recommended, among other changes needed to improve access to different forms of respite, that subsidies and supplements for respite care in residential facilities at least be brought into line with those available for permanent care.

There has been no Government response to this recommendation or, to the best of our knowledge, other recommendations of the ACFA report. ACFA did acknowledge that a review of respite subsidies should probably be considered in the context of decisions around the proposed new Australian National Aged Care Classification (AN-ACC) model for determination of needs assessment and funding for residential aged care. However, Professor Kathy Eagar, who led the Australian Health Services Research Institute's (AHSRI) into this classification system, has made it clear that, in their view, adjustment of respite funding would require a separate review. Even if respite was included in the implementation of the AN-ACC, final approval and implementation of the model will take some considerable time.

## **Access to respite through home care programs**

It is our strong view that respite will not be properly addressed and carers will not receive the recognition and support they deserve while their entitlements and services are treated as a sub-component of the support to those they care for.

### **Assessment of the carers' needs**

Carers' needs can be assessed as supplementary to the needs assessment of those they care for. The problems are that there are no requirements to seek carer participation in the assessment, and that carers are often not aware that they can participate and that their needs can be considered. This is the same for assessments through the Regional Assessment Services (RAS) and Aged Care Assessment Teams (ACATs or ACARs).

Carers Australia strongly supports the recommendations of Counsel Assisting, Peter Gray QC, that: "Supports for informal carers (including education and counselling) and respite should be the subject of specific assessment".

(Counsel's Assisting submissions on Program Redesign, 4 March 2020,

<https://agedcare.royalcommission.gov.au/sites/default/files/2020-06/submissions-by-counsel-assisting-4-march-2020.pdf> / p.14)

## **Funding of carer support needs identified in assessments**

It is also our view that carer supports through aged care need their own program and funding. The current arrangements in relation to Home Care Packages, where supports services for carers must be taken from the package of those they care for, has led to perverse outcomes.

For example, while subsidised cottage respite is available to someone with low care needs through the Commonwealth Home Care Program, carers of someone with higher care needs wishing to obtain cottage respite will be charged full cost recovery out of the Home Care Package. Not only does this draw significantly on the funds available to support recipients to allow them to remain in the home, but it is also seemingly paradoxical that those carers of people with high care needs, who are likely to be most in need of planned respite, have to shoulder the costs without the subsidisation available to those whose caring roles are likely to be much lighter. While Home Care Packages can lighten the load of family carers, continuous emotional support, vigilance, worry and social isolation tends to come with looking after someone with very high care needs. This is markedly so in the case of carers of people with challenging behaviours, such as dementia.

The extent to which carers' needs are addressed through Home Care Packages is unknown since the Department collects no data on this. Carers need their own funding support, separate from that provided to the package recipient.

In his witness statement to the Royal Commission on 4 March 2020 on future aged care program design, Senior Counsel Assisting, Peter Gray QC, made the following recommendations:

“Comprehensive assessment for eligibility for aged care should give attention to the needs of informal carers for older Australians in their own right, leading to quarantined entitlements for informal carers to receive support services, such as counselling and training, and also for them to receive respite.”

(Testimony of Senior Counsel Assisting on the Future of aged care program redesign, 4 March 2020, Transcript, <https://agedcare.royalcommission.gov.au/publications/counsel-assistings-submissions-program-redesign>, p.7907)

### **Shortage of cottage respite**

Respite stays outside the home offered in residential aged care are generally not the preferred option either for carers or the people they care for. There are many disadvantages. These include:

- Many places are booked months in advance, while in other places respite cannot be booked far enough ahead and for the times it is needed (for example, so carers can plan and book holidays).
- Residential aged care facilities usually impose minimum stay periods, often of two weeks, which does not suit many carers, who may need, or prefer, to have shorter and more frequent breaks.
- Moving to an institutional environment can be a very alien and disconcerting experience.
- Delays in ACAT assessments mean that carers are often unable to access respite when they need it.

One form of out-of-home respite, which is particularly favoured, is dedicated respite accommodation offering day and overnight care in a more home-like environment than residential care, often referred to as cottage respite. This type of respite can be used for both planned and emergency care. The facility may be stand-alone or may be attached to day care facilities.

Advantages are:

- The older person may use these facilities for day care, with occasional overnight stays, and so are in familiar surroundings with people they know. This can be particularly important for people with dementia.
- Stays are in a house or homelike environment, rather than an aged care facility, so it is more normalised than residential respite in an aged care facility and may even feel like a holiday for the consumer.
- Cottages offer dedicated short-term stays only and respite clients are not competing with people and providers using short-term residential accommodation as a prelude to entering permanent residence.

- There is greater flexibility. Residential respite is generally only available for a period of two weeks or more, but cottage respite can suit carers who prefer to have one- or two-nights respite more regularly, rather than blocks of respite, or can be used in combination with blocks of care. For example, a carer may have a two-week holiday once a year and a night or two break in other months.

The problem is that there are comparatively few such facilities available and those that are available are designed to accommodate a small number of clients. Just how many cottage respite services are available appears to be in some contention. According to the aforementioned ACFA report, there were just under 100 providers of cottage respite in Australia in 2017-18. However, Hammondcare in its submission to the Commission's Consultation Paper on Program Design in Aged Care, points out that the MyAgedCare platform lists only 55 cottage respite services currently in operation, and that only 24 cottages operate seven days a week in stand-alone community settings.

(Hammondcare Submission to the Royal Commission on Aged Care Quality and Safety on *Redesigning the aged care system in Australia*, January 2020

<https://agedcare.royalcommission.gov.au/submissions/read-published-submissions/consultation-paper-1-submissions>)

There are simply not enough cottage facilities to accommodate demand.

Disincentives for providers to invest in cottage respite include that capital funding, refurbishment and fit out costs cannot be claimed under the Commonwealth Home Support Program (CHSP) which finances this form of respite. This is in contrast to residential aged care. Hammondcare, in its 2019 Pre-Budget Submission noted that there had been no additional Commonwealth funding for cottage respite in over a decade. They advocated an expansion of block funding agreements through grants of up to \$1 million, depending on the hours and days of support offered, to expand the number of these facilities. They also proposed zero interest loans to expand the number of services available. Such funding could be used to support the purchase of land and construction or capital upgrades and renovations for rental properties.

(Hammondcare, *Pre-Budget Submission 2019-20: Cottage Respite Proposal*,

<https://treasury.gov.au/sites/default/files/2019-03/360985-Hammondcare.pdf>)

Another issue is that Commonwealth Home Support Program Guidelines, including those in relation to subsidised community respite, recommend the support should not exceed that which is the equivalent of a level one Home Care Package, currently capped at \$8,000. In her evidence to the Mildura hearings, Ms Buffington, representing the Department of Health, identified that the cost to the Government of subsidising cottage respite is about \$700 a night. (Royal Commission into Aged Care Quality and Safety, Mildura Hearing, 31 July



2019, Transcript, p.4140, <https://agedcare.royalcommission.gov.au/media/12701>). This amount would provide 11 nights of subsidised respite, noting that carers can access up to 63 days of residential respite which can be extended for another 21 days under special circumstances. This disparity in access to respite for older Australians is inequitable. The ACFA review recognised that cottage respite is in effect another type of short-term residential respite care and should be treated as such when considering neutrality of funding settings.

## **Urgent need to restore the focus on carers**

As evidence put to the Commission has shown, there is a pressing requirement to address the flaws in the provision of supports such as respite to carers of the aged. And this need must be addressed now and taken seriously as an issue to be dealt with in its own right. If, as has happened in the past, carers' needs are put off indefinitely until other reforms to the aged care system have finally been adopted, there is unlikely to be a timely resolution to what is an area of high need, in need of urgent reform.

It is not necessary to wait for the Australian National Aged Care Classification (AN-ACC) model currently being piloted to be refined, approved and implemented before the inadequate allocation of respite subsidies in residential aged care is addressed. The decision can be made in the short-term to implement the advice of the Aged Care Funding Authority to increase the subsidies for respite provision to at least the level where they reflect the subsidy for permanent residents.

The decision can also be made in the short-term to extend capital funding for cottage respite.

In addition, a decision can be made to introduce and implement a separate assessment of carers' needs through both the Regional Assessment Services (RAS) and the ACAT prior to the implementation of a single system of assessment.

Further adjustments to carer supports may need to be made in the future as a result of changes to other aspects of the aged care system.

Finally, it is Carers Australia's view that there needs to be responsibility and accountability for informal carer support within the Department of Health. There is a diffusion of responsibility for respite supports across a number of aged care branches in the Department, and respite does not appear to be a high priority within the Aged Care Group.. There would be merit in carer supports being brought together in a dedicated place within the Department's structure.