



Pre-Budget submission 2018-19

DECEMBER 2017

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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EXECUTIVE SUMMARY

Deloitte Access Economics estimated that, in 2015, unpaid family and friend carers provided 1.9 billion hours of care with a replacement value of \$60.3 billion.¹ National government funding for carers in 2015-16, in carer related social welfare payments and direct carer services, represented about 2 per cent of this replacement value.²

Despite widespread political and community recognition that the contribution of unpaid family and friend carers is essential to the continuing affordability of aged care and disability care, direct funding for support services to assist carers with their own needs has been declining over a number of years.

The projected introduction of a new Integrated Carer Support Services (ICSS) model to help rectify this situation and improve services to carers has not yet been endorsed by the Government. In the meantime, the demand for carer support services will continue to grow as the population ages and with the growth in carers' awareness of entitlements and knowledge of available support services following from the establishment of the Carer Gateway.

Carer Support Funding is declining

Funding for carer supports is draining away as a large proportion of that funding is continuously transferred into the NDIS.³ Carers of people with poor mental health are likely to be the most affected since the funding for the Mental Health Respite: Carers Support (MHR:CS) program, which was the second highest funded carer support service in 2015-16 and supported 40,644 people in 2014-15, has been committed to NDIS-rollout.⁴ The transfer of this funding is particularly ill-targeted since it has been widely acknowledged that people with psychosocial disability are the most disadvantaged in qualifying for NDIS packages and that, in the meantime, funding of mental health support services is being withdrawn or transferred into NDIS revenue at both the national and state levels. It is also of note that the Australian Bureau of Statistics (ABS) 2015 Survey of Disability, Ageing and Carers identified that carers of people with mental health and behavioural disorders constituted the highest proportion of all co-residing primary carers (28.6 per cent of the total).⁵

¹ Deloitte Access Economics (DAE), *The economic value of informal care in Australia in 2015*

² Calculated on the basis of carer support programs funded by the Department of Social Services identified in Department of Social Services, *Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016* and carer specific welfare payments Budget 2017-18: Portfolio Budget Statements 2017-18: Budget Related Paper No. 1.15A: Social Services Portfolio, Commonwealth of Australia 2017, p 41-42

³ As part of the initial bilateral agreements to fund the NDIS, the Commonwealth Government committed funding from three dedicated carer support programs - which include the provision of respite, information and referral, and counselling - for transition into the NDIS funding pool. In 2015-16, the funding for these programs was \$78.628m and constituted about 46 per cent of total Department of Social Services carer support funding in 2015-16.

⁴ Department of Social Services, *Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016*

⁵ Australian Bureau of Statistics (ABS), 2015 Survey of Disability, Ageing and Carers (SDAC), SDAC Table Builder.

Recommendation 1

Regardless of whether or when the Integrated Carer Support Service model is introduced, there is a current need for an injection of funding to services that is at least equivalent to 2015-16 Department of Social Services (DSS) expenditure on carer support services.

Contracts terminating in June 2018

In addition, many contracts for a large suite of carer support services have a termination date of end June 2018 (the date when it was originally thought that the new ICSS model would be implemented). These short contracts are undermining the capacity of service providers to plan in advance and to offer continuity of services to their clients.

Recommendation 2

Contracts for delivery of existing carer programs, which have a termination date of 30 June 2018, should be renewed for at least two years to allow service continuity.

Access to respite for carers of the aged

Carers of the aged are also struggling to get access to residential respite (including emergency respite) since the *Living Longer Living Better* aged care reforms were introduced. There are a variety of reasons for this which are explored below. As recommended in the recently released *Legislated Review of Aged Care 2017*, the existing respite arrangements should be reviewed to make sure that the objectives are being met.⁶ While there are a number of best practice options for overnight and longer term respite accommodation which could be pursued outside the traditional residential aged care setting, a sensible reform in the context of existing infrastructure would be to introduce incentives through existing residential aged care subsidies, so that respite admissions are more attractive to providers. As matters stand, the respite daily subsidies are significantly lower than permanent daily subsidies, even though it requires significantly more administration and disruption to offer short term care.

Recommendation 3

At a minimum, the Government should increase residential aged care subsidies for respite in order to increase the supply of respite beds.

Recommendation 4

The Government should work with state and territory governments and community organisations to fund an expansion of cottage style respite care facilities and places.

⁶ *Legislated Review of Aged Care 2017*, Recommendation 8, p.13

Welfare reform

Welfare reform is a third area which is negatively affecting carers. The four Social Services Bills introduced to Parliament over the Winter (Budget) Session, if passed, will impose additional financial burdens on already struggling carers who receive the Carer Payment. Especially concerning is the removal of intent to claim provisions, which will significantly delay payments to carers who suddenly find themselves unable to work because they have to take on significant caring responsibilities. Also of particular concern is the removal of the Energy Supplement to new Carer Payment recipients, especially at a time of soaring increases in energy bills. Other measures that are likely to cause financial distress to many pensioners and those who care for them are longer residency requirements for Aged Pension and Disability Support Pension and changes to the Education Entry Payment (EEP) and the Pensioner Education Supplement (PES), which will make it harder for a number of carers to access education. Neither of these measures will yield much in the way of Budget savings.

Recommendation 5

The following measures that will affect carers, proposed in Bills to amend the Social Security Act 1991, not be enacted:

- *changes to reduce entitlements to Entry Education Payment and Pensioner Education Supplement*
- *abolition of the Energy Supplement*
- *longer new resident waiting periods for Aged Pension and Disability Support Pension*
- *removal of intent to claim provisions for income support payments*
- *extension of the mandatory Cashless Debit Card to new locations.*

Carers Australia supports the position taken by ACOSS that payments for single allowance recipients be increased by \$75 per week to give them the capacity to meet a minimum income standard for low paid and unemployed Australians, as measured by the Social Policy Research Centre of the University of New South Wales.⁷ Newstart payments, partly as result of poor indexation arrangements which have driven down the value of the allowance over time, are well below the poverty line. We note that many carers, who provide a great deal of care but who do not meet the eligibility requirements for the Carer Payment, will be on Newstart, and that they may be on the Newstart payment for a considerable period of time if their caring responsibilities make it difficult for them to find and maintain employment.

Recommendation 6

That the rate of Newstart Allowance and related payments for single people and sole parents be increased by \$75 per week and that future increases be tied to Age Pension indexation.

⁷ Saunders, P and Bedford, M (August 2017), *New Minimum Income for Healthy Living Budget Standards for Low-Paid and Unemployed Australians*, SPRC UNSW

PROGRAM DESIGN AND FUNDING FOR CARER SUPPORT SERVICES

While it is true that unpaid family carers generally benefit from improved formal support for the people they care for, this does not remove all the stresses relating to the caring role and the need for carers to be able to access core support services to meet their own needs and bolster their own wellbeing. Such services include the capacity to find replacement care (whether short term or longer term) in order to take a break from caring (whether in an emergency or planned). Services that are needed also include counselling, training, peer support, advocacy, and information and referral to organisations which can assist them with a range of issues relating to their caring role. These needs were not adequately recognised when the *Living Longer Living Better* Aged Care reforms and the National Disability Insurance Scheme were designed and implemented.

Funding previously available for carer support at both the national and state level has been diverted into programs that provide direct support to those they care for on a consumer-directed-care basis. In addition, constraints on access to higher level support for the people they care for also impacts on carers. In the case of aged care, the capping of home care package numbers and consequent delays in access to packages for the consumer also affects the carer and the care load. In the case of the NDIS, many carers will not necessarily care for someone who meets the NDIS eligibility requirement – that is, the disability might not be permanent, even though it can require high levels of care over long periods while it is active. This is conspicuously the case for carers of people with mental health conditions, where it is estimated that over 200,000 Australians living with complex and sometimes severe mental illness will not be eligible for the NDIS.

In addition, as a result of aged and disability care reforms, there was a split between carer support entitlements for those who care for people over the age of 65 years and those who care for someone under the age of 65 years. Many carers care for both someone over 65 years old **and** for someone under 65 years old. This has created a fracturing in access to carer-specific services for these sandwich carers, which is most obvious in relation to respite care, where entitlements and access rules under aged care are very different to those under the NDIS guidelines, making coordination of respite opportunities very difficult.

Partly in recognition that aged and disability reforms had splintered carer supports, and partly in recognition that carers needed and deserved a better system for the delivery of supports, the Government announced funding in the 2015-16 Budget for development of a Carer Gateway and the development of an Integrated Plan for Carer Supports to streamline and coordinate services for carers. Over the following two years, an Integrated Carer Support Services (ICSS) model was developed by the Department of Social Services (DSS) in consultation with the sector. This model introduces root and branch reform to service architecture. In addition to creating a whole new hierarchy for the delivery of carer services from the national, through the regional, to the local level, it includes a number of new activities and service support types. Carers Australia has been supportive of the model, although concerned about some of the unknowns. One of the unknowns is the configuration and number of regional “hubs”. Another is the extent to which the new model has, or will be, properly costed and funded. Our very strong view is that, if it is not properly funded, carers could well be worse off than under the current nationally funded carer support architecture.

In addition, in expectation that the ICSS would be introduced in mid-2018, plus the fact that some carer programs would be transitioning to the NDIS, contracts for Department of Social Services' existing carer support service programs were given short termination dates.

The Government has not yet made an announcement with respect to the ICSS model.

Regardless of whether or when the ICSS is implemented, there is a pressing need to address the ever increasing service gaps which have emerged through aged and disability care reforms, and to account for the growth in the number of carers seeking support services. This growth in demand relates partly to the ageing of the population, partly to the loss of support to people with disability who will not qualify for NDIS packages, and partly to the establishment of the Carer Gateway, which has been designed to alert carers to their entitlements and the type of supports they can access. With respect to the latter, from launch on 14 December 2015 to 31 August 2017, there were 507,532 visits to the Carer Gateway website. Website visits have been growing steadily since the launch, with visits in May 2017 the highest since launch at 36,396. Seventy-three per cent of visitors are new visitors, indicating that new users are finding and accessing the website.

Recommendation 1

Regardless of whether or when the Integrated Carer Support Service model is introduced, there is a current need for an injection of funding to services that is at least equivalent to 2015-16 Department of Social Services' expenditure of carer support services.

Recommendation 2

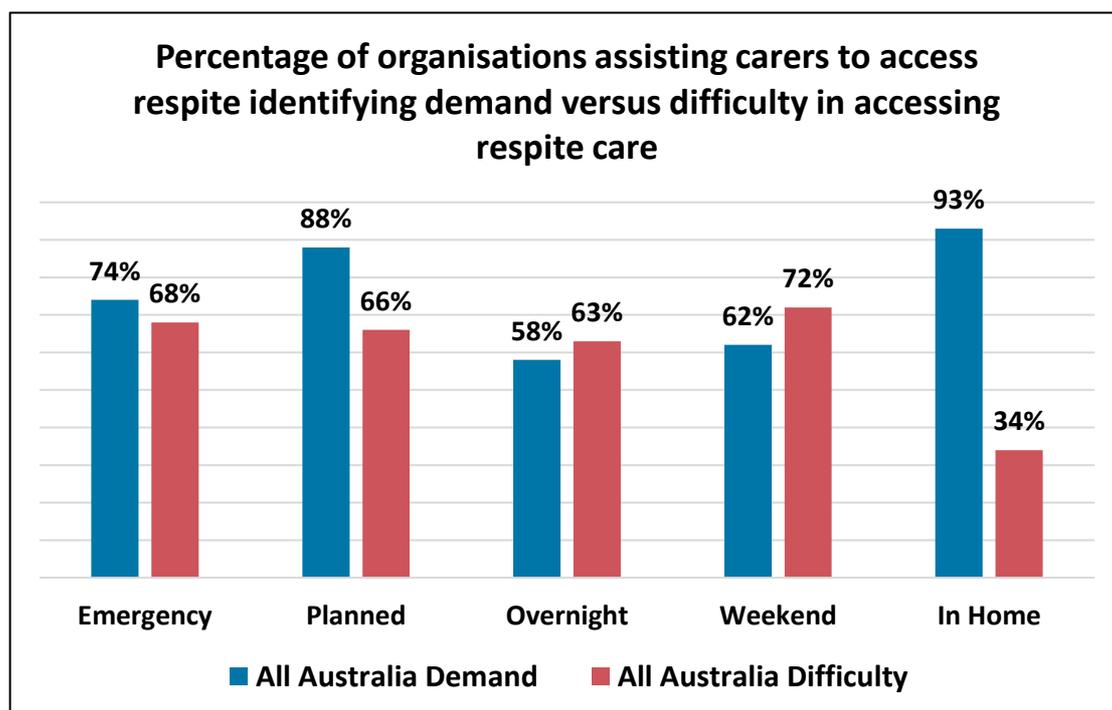
Contracts for delivery of existing carer programs, which have a termination date of 30 June 2018, should be renewed for at least two years to allow service continuity.

AGED CARE – RESIDENTIAL RESPITE SERVICES

Carers of the aged need to have breaks to enable them to continue to provide care at home. Without access to respite services, carers are likely to burn out, especially if they are caring for someone with complex needs, and may find themselves unable to continue to provide care at home. As a result, those they care for are likely to move into permanent residential aged care. Reports that carers are struggling to access residential respite when they need it, including in emergencies, are widespread. The recent report of the *Legislated Review of Aged Care 2017* recommended a review of existing respite arrangements to make sure that objectives are met.⁸

⁸ *Legislated Review of Aged Care 2017*, Recommendation 8, p.13. The Review comments that Department of Health data in the 2016-17 Report on the Operation of the *Aged Care Act 1997* indicates that instances of residential respite have increased, however does not really test alternative

As a result of anecdotal reports from the network of state and territory Carers Associations and other services which assist carers to access respite of increasing difficulty in accessing respite care in residential aged care facilities, Carers Australia undertook a national survey of these organisations to identify the extent of shortages and the reasons for them. We received over 100 responses from across the country. It became clear from the survey that there are systemic issues hampering availability of residential aged care respite places. While the level of demand varied, with the greatest number of respondents indicating high or very high demand for planned respite (88 per cent), between 63 per cent and 68 per cent reported that it was difficult or very difficult to access residential respite care. This contrasts with in home respite care, with only a third of respondents reporting any degree of difficulty.



The survey results clearly identified significant issues, including:

- not enough residential respite care beds, particularly for:
 - people with lower care needs (due to low subsidies)
 - people with high needs, and
 - dementia specific respite care.
- many residential aged care facilities are not offering any respite care or only offering a bed when it is between permanent residents
- not being able to get bookings well in advance and for the times they are needed (for example, so carers can plan time away)

uses of these “respite” beds which may be more attractive to providers, including hospital transitions and potential permanent residents seeking “try before you buy” experiences.

- difficulties meeting transport needs, particularly relating to distance from home to the aged care facility, including for the carer arranging transport and visits by other family members
- many residential respite providers are unable to provide secure settings and/or (enough) trained staff to support people with dementia and others with high care needs
- inflexible minimum stay periods
- delays in ACAT assessments required to access respite care, and
- transition from acute care in hospitals for the purposes of recovery taking up potential respite care beds.

The table below sets out the daily subsidies paid to residential care providers, based on type of care and the residents' care needs. Taking the lowest rates for low and high permanent care, it is apparent that permanent care subsidies are, as a rule, higher than for respite care. The transitional care subsidy for residential care is highest, with contributions from both Commonwealth and state/territory governments. The much lower subsidies for respite are a major disincentive for providers.

Daily Government subsidies paid to residential aged care facilities

	Permanent (tabular structure)	Short Term Restorative Care	Transitional Care	Respite (low care)	Respite (high care)
Basic subsidy (daily)	\$61.39 to \$214.06	\$193.34	\$350.99*	\$45.45	\$127.46
Needs supplement	\$45.45 to \$247.04		\$3.99	\$37.74	\$52.90

* Varies across states/territories. Commonwealth subsidy \$198.99 (figure provided based on Victoria).

While a major factor, the low subsidies are not the only disincentive. Other reasons why aged residential care providers may not be responding to respite needs are:

- use of respite beds to accommodate potential permanent residents (“try before you buy”)
- use of respite beds to accommodate people transferred from hospitals (which attracts a very high subsidy)
- less likelihood of full occupancy of respite beds than permanent beds and, therefore, less predictability for staffing and other running costs
- additional resources for respite, with administrative requirements for each person and additional support to help them settle in to the accommodation.

Recommendation 3

At a minimum, the Government should increase residential aged care subsidies for respite in order to increase the supply of respite beds.

Aside from the need to review subsidies for residential aged care respite, alternative forms of respite are also needed. Increasing the supply of cottage style accommodation offering overnight and weekend respite (which is generally preferred to residential respite by both carers and consumers) was one of the most called for improvements by survey participants to address the shortage in availability of short term (overnight and weekend) care.

The advantages include:

- where accommodation is attached to day care facilities the care recipient is in familiar surroundings with people they know
- overnight stays are in a house, rather than an aged care facility, so it is more normalised than residential respite in an aged facility
- cottages offer dedicated respite care, so there is a known number of beds and respite clients are not competing with people looking for permanent residence or people transitioning from acute care
- there is greater flexibility, and can suit carers who prefer to have one or two nights respite more regularly, rather than large blocks of respite preferred by residential aged care facilities, or can be used in combination with larger 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)
- it can take pressure off residential facilities that have competing high demands from consumers seeking permanent residence and those seeking respite care.

While a more costly model than other forms of aged respite care, Carers Australia argues that the benefits to the community and alleviation of pressure on other parts of the aged care system are likely to justify costs. Moreover, some of these costs can be reduced through innovative practices, for example through co-location with other services and adopting practices to minimise vacancies, such as allowing city cottages to be occupied by regional (carer/consumer) families travelling together for a hospital stay or break.

Recommendation 4:

The Government should work with state and territory governments and community organisations to fund an expansion of cottage style respite care facilities and places.

SOCIAL SERVICES MEASURES AND PAYMENTS

In 2017, Carers Australia made submissions to the Senate Community Affairs Committee inquiry into the proposed amendments of the *Social Security Act, 1991*, through a number of Social Services Legislation Amendment Bills:

- Better Targeting Student Payments Bill
- Carbon Tax Compensation Bill
- Payment Integrity Bill
- Welfare Reform Bill
- Cashless Debit Card Bill.

Carers who rely on income support payments face significant financial disadvantage, including through the extra costs of providing full time care. Carers Australia considers that a number of the measures in those bills will adversely affect carers and has asked that:

- carers and other social security recipients continue to receive the Entry Education Payment and the Pensioner Education Supplement at current levels, with no interruption during semester breaks and holiday periods
- the Energy Supplement continue to be paid to new income support recipients who face electricity and gas prices that are increasing at a far higher rate than indexation to their income support payments
- current new resident waiting periods for Aged Pension and Disability Support Payment remain unchanged
- current intent to claim provisions for social services payments, including Carer Payment, remain unchanged
- the Cashless Debit Card not be extended to new locations without further evaluation of its effectiveness in current locations.

Carers Australia also supports the call by the Australian Council of Social Service (ACOSS) and other organisations in the community and business sectors to increase the News tart Allowance (and other allowances paid at the same rate) in line with community standards.

The rate of News tart and like allowances is a critical concern to many carers. While many carers receive a pension rate of assistance through Carer Payment or through other pensions, many others are not eligible for these payments, but rather rely upon News tart or other allowances for support while undertaking their caring responsibilities. In addition many carers live in households where an allowance rate of income support is part of the household income. This is one of the factors linked to the low income and financial stress so many carers experience. Further, in those cases where a carer ceases caring, very frequently due to the death of the person they have been caring for, or because the person moves to residential care, many carers lose their entitlement to their former income support and find themselves on an allowance payment.

In each of these cases we believe that the rate at which allowances are paid is manifestly inadequate. We note that one explanation for the differential between the rate of the News tart Allowance and pensions is the expectation that those on allowances will be able to support themselves in the workforce in the near future.⁹ This assumption is not valid for a high proportion of carers. Even if not caring full-time, the demands of caring severely limit the capacity of many carers to undertake substantial and sustained employment, while those attempting to enter the job market face many barriers including low levels of work experience, education and training, frequently as a consequence of their caring.

Carers Australia supports the position taken by ACOSS that payments for single allowance recipients be increased by \$75 per week to give them the capacity to meet a minimum income standard for low paid and unemployed Australians, as measured by the Social Policy Research Centre of the University of New South Wales.¹⁰ It will not, however, be enough in the longer run to have a one-off increase if the gap will again widen between the payment rate and minimum income standards. This should be alleviated by using the same indexation method for allowances as is used for pension rates which takes into account both CPI and rises in weekly earnings.

Recommendation 5

The following measures that will affect carers, proposed in Bills to amend the Social Security Act 1991, not be enacted:

- changes to reduce entitlements to Entry Education Payment and Pensioner Education Supplement
- abolition of the Energy Supplement
- longer new resident waiting periods for Aged Pension and Disability Support Pension
- removal of intent to claim provisions for income support payments
- Extension of the mandatory Cashless Debit Card to new locations.

Recommendation 6

That the rate of News tart Allowance and related payments for single people and sole parents be increased by \$75 per week and that future increases be tied to Age Pension indexation.

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¹⁰ Saunders, P and Bedford, M (August 2017), *New Minimum Income for Healthy Living Budget Standards for Low-Paid and Unemployed Australians*, SPRC UNSW