



Federal Election 2019: Commitments sought to improve the lives of carers

Carers Australia values the widespread political and community recognition of the value of Australia's unpaid family and friend carers, both to society and the economy. It is also widely understood that providing care to family members or friends often comes at personal cost, including to their own health and wellbeing.

While there are a number of areas of government policy which have an impact on the wellbeing and future prospects of family and friend carers, Carers Australia has identified six high priority issues of immediate concern which need to be addressed by the Federal Government:

- Reverse the decline in funding for direct support services available to carers
- Redress the decline in access to respite care within the aged care sector
- End lengthy waiting periods for access to aged care Home Care Packages and ensure that supply meets assessed need
- Improve delivery of the NDIS
- Improve opportunities for carers to take up employment
- Support research to identify and address the problem of extensive and persistent sleep deprivation among carers.

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Reverse the decline in funding for support services available to carers

- In March 2018, the Government announced its intention to roll out a new, streamlined Integrated Carer Support Service (ICSS) model to replace the currently fragmented system of carer support services and gaps in direct carer support services which have emerged from aged care reform and the implementation of the NDIS. The new program will be implemented from September 2019.

What we know

- Carers Australia and other carer organisations had expected funding for the new model would be maintained at least at current levels of Commonwealth government support for carer services, and preferably additional funding given the growth in the number of people needing support from family and friend carers.
- In 2017-18 funding for direct carer support services was \$161.9 million, excluding \$7.6 million for the Carer Gateway website. However, funding identified for the new program when it was announced in 2018 identified a budget of \$80.2 million in 2019-20, \$72.2 million in 2020-21, and \$106 million by 2022-23 for the delivery of direct services to carers. The magnitude of the loss of funding for direct services was daunting.
- The Carers Australia's pre-Budget submission put the case that at least 30 per cent of funding previously redirected from carer respite services to the NDIS should be reimbursed in the funding arrangements for the ICSS model and that this funding should be invested in planned respite.
- The Treasurer's 2019-20 Budget announcement of an additional \$84.3 million to the ICSS over the Forward Estimates was a welcome response to concerns about reduced funding. However, the 2019-20 Budget Measures have yet to pass through Parliament.



Election commitment sought

- That the \$84.3 million commitment to the new Integrated Carer Support Services in the 2019 Budget be supported and honoured.
- An independent review of the performance of the new Integrated Care Support Service system two years after it has been rolled out. The review should assess the effectiveness of its design, whether it is meeting demand, whether online digital services and Regional Delivery Partners have been able to meet service requirements, and if there are any service and funding gaps in the model.

Improve access to aged care respite

Aged Care Respite

Access to subsidised respite opportunities for carers of the aged is getting harder to access.

What we know

- Carers Australia recently conducted a survey of Commonwealth Respite and Carelink Centres (CRCCs) and similar providers to ascertain the availability of residential aged care for the purposes of planned and emergency respite. We found that:
 - there is a very high demand for both emergency and planned residential respite care
 - there are not enough planned or emergency respite beds, particularly for people with high care needs, including dementia
 - Government subsidies paid to residential care operators are much lower for respite than permanent care, even though the upfront costs associated with short-term care are high
 - as well as places in residential aged care, where services are often only available in two-week blocks or longer, there is a high demand for, and a low supply of, overnight and weekend respite in more informal settings, such as respite cottages.
- In 2018 the Aged Care Financing Authority (ACFA) undertook a review of residential respite care which confirmed that residential respite care places in recent years were being used for purposes other than to assist older people to continue living at home and to give their carers a break. ACFA made 17 recommendations to improve respite care services, including establishing funding arrangements that are neutral between respite residents and permanent residents, so as not to act as a disincentive to offering respite care.



Election commitments sought

- **Implementation of the Aged Care Financing Authority's recommendations with respect to residential respite, including a new funding model that removes disincentives for residential respite providers to provide short term accommodation for the purposes of respite care.**
- **A review of options and incentives to increase the provision of short-term accommodation outside of residential aged care facilities.**

Improved Access to Home Care Packages

Older Australians can wait for more than 18 months after their need for support is assessed before they can access a Home Care Package. A large increase in packages at appropriate levels is needed so that these numbers don't continue to increase.

What we know

- Older people prefer to live independently in their own homes for as long as they can.
- The Home Care Support Program has four levels of funding to help older people buy support services, equipment and home care modifications to help them stay in their homes. The demand for lower level (1 and 2) Home Care packages is going down, while it is going up for higher level (3 and 4) packages, creating long waiting lists for appropriate levels of support.¹
- More than 125,000 older Australians are in limbo waiting for appropriate levels of home care with many yet to receive any support at all.²
- In the meantime, their level of health is likely to decline and their need for support increase, making it difficult to live at home unless they have family and friend carers who can provide the level of care they need. Working carers may have to give up their jobs, while partner carers may also be ageing and not able to provide the level of care needed, or can only do so at the risk of compromising their own health and wellbeing.

Election commitments sought

- **Home Care Packages to be increased to meet assessed need and demand.**

¹ <https://www.cota.org.au/wp-content/uploads/2018/09/Policy-Paper-Five-Fixes-Aged-Care-September-2018-FINAL-SOFT-COPY.pdf> p10

² According to the National Aged Care Alliance (NACA).

Improved disability service delivery and sustainability

The National Disability Insurance Scheme (NDIS) has been operating under a staffing cap that has created delays for getting participants into the Scheme and many services are being delivered by contract staff. At the same time, the NDIS has absorbed funding from many other programs that are being discontinued, while not providing alternative programs for people who will not be eligible for the NDIS, including many people with psychosocial and other episodic conditions.

What we know

- The Productivity Commission recommended removal of the staffing cap because of the adverse effect on delivering the NDIS.
- Having enough permanent staff to support NDIS participants will ease delays in planning and reviews and increase expertise in disability needs.
- Programs were funded in the 2018 Budget to ensure continuity of care for people who will not be eligible for participation in the NDIS. These programs will not admit new participants.
- Carers Australia welcomes the Australian Labor Party's commitment to lift staffing caps.

It has been reported that the NDIA has underspent its budget from the beginning of roll-out; Carers Australia wants an assurance that these unspent funds will be retained by the NDIA to ensure the continuing sustainability of the Scheme as it was intended and not allocated to other Government spending priorities.

Election commitments sought

- **The staffing cap for the NDIS be lifted.**
- **Continued funding for programs to support people with conditions that not eligible for the NDIS, particularly people with psychosocial and other episodic conditions.**
- **Unspent NDIS funds to be spent on the Scheme as it was intended**

Improve opportunities for carers to take up employment

Reduced participation requirements for carers on Centrelink jobseeker payments

Many unemployed carers who provide substantial care, but not enough to qualify them for the Carer Payment, receive Newstart Allowance. At the same time, the care they provide can be a barrier to finding suitable employment and to meeting Newstart eligibility requirements, including to seek full time employment (of more than 30 hours a week) and to meet Newstart job search requirements.

What we know

- Carers who receive Newstart Allowance but are providing enough care to receive Carers Allowance, need flexibility to search for work that is compatible with their caring role.
- There is no recognition of the economic contribution of providing unpaid care, and the hours of care provided are not included as a measure of meeting participation requirements.
- Participation in the labour market could be better achieved by addressing barriers to gaining and maintaining employment, rather than setting job search requirements.



Election commitment sought

- **Job search requirements which take reasonable account of the ongoing caring responsibilities of jobseekers, for example by including hours of unpaid care as a participation activity, and by providing flexibility for carers to seek part-time work to accommodate their caring responsibilities.**

Transition from care to paid work

Many carers give up paid work to become full time carers and, sometimes, because of disincentives built into the payment system, are unable to maintain a connection to the labour market. Carers who want to re-enter the labour market after a long absence would benefit from intensive support and assistance, including access to counselling and training.

What we know

- According to the 2015 Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC):
 - more than a third of primary carers are providing more than 40 hours of care a week and typically spend between one and nine years in their caring role; more than two-thirds are women
 - working age carers are far more likely than their peers to be outside the labour market and nearly half rely on government payments as their main source of income
 - more than two-thirds of carers of working age continue to receive income support payments when they no longer qualify for Carer Payment.
- To qualify for Carer Payment, full time care must be provided. In practice, this means that anyone who is working, in education or providing volunteer services for 25 hours a week or more (including travel time) may not qualify for the Payment. While working for more than 25 hours should trigger a Centrelink review, many carers report that their payments are cancelled immediately, creating a disincentive to take on even short term employment, education or volunteer work.
- While the Department of Jobs and Small Business' Jobactive program is open to carers on Carer Payment, they may find it hard to access the available support services.
- The Transition to Work program, offering intensive support for young people aged 15 to 21 years entering the labour market for the first time, may offer a more appropriate model of support for working age carers than the Jobactive program. This would be consistent with the recommendations of the Employment Services Expert Advisory Panel, *I want to work: employment services 2020*, that there should be more flexibility in employment support for job seekers.

Election commitments sought

- **Improved availability of employment services offered to former and current carers who would like to enter or re-engage in the labour market when their caring role diminishes or ceases.**
- **Access to intensive support for carers, through Jobactive and other existing and new programs, that will help them to build their confidence, identify training and employment opportunities, deliver appropriate training and develop practical skills to help them find employment.**
- **A review of Social Security Act provisions and guidelines to enable greater flexibility for Carer Payment recipients to participate in education, training and part time and/or short term employment.**

Fund research and measures to support carers who are sleep deprived

The impact of continuing sleep deprivation has become a national health concern, as highlighted by a recent report from a House of Representatives Committee Inquiry into Sleep Health Awareness.

Many carers, especially when providing high level and/or complex care suffer sleep deprivation every night, often for years or decades. For example, the carer might need to:

- help the care recipient use the toilet, to turn them in bed, respond to seizures or choking or administer medications
- be constantly vigilant, especially when caring for someone with a mental health condition, learning disability or cognitive condition like dementia, where the person being cared for can wander or get distressed during the night.



What we know

- Nearly half of all primary carers have reported interrupted sleep, which has been identified as having the single biggest negative impact on the wellbeing of carers.
- Carers Australia has partnered with the Sleep Health Foundation to conduct a literature review of research into the incidence and effects of sleep deprivation on carers.
- This initial study has highlighted how little research there has been on this issue.
- Further funding is required to address this knowledge gap both in terms of the parameters of the problem and the interventions required to address it.

Election commitment sought

- **Funding for a large scale study of sleep deprivation in carers, including:**
 - **measuring the number of people affected, the extent of sleep disruption/loss**
 - **the nature and diversity of sleep disruption**
 - **the effects of sleep deprivation on carers' health and wellbeing**
 - **the effects on people with care needs and other family members**
 - **the best methods to support carers who are sleep deprived.**