



Carers Australia Pre-Budget Submission 2016–17

More responsive carer supports

January 2016

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.

For information contact: Ara Cresswell,
Chief Executive Officer
Carers Australia

Unit 1, 16 Napier Close
DEAKIN ACT 2600
Telephone: 02 6122 9900
Facsimile: 02 6122 9999
Email: acresswell@carersaustralia.com.au
Website: www.carersaustralia.com.au

Table of Contents

Executive Summary and Recommendations	pages 1-2
Discussion of Issues and Recommendations	
Issue 1: Integrating and aligning general support services for carers	pages 3- 4
Issue 2: Wrap-around support for carers with complex needs	pages 4-7
Issue 3: Assisting carers and former carers to transition to the workforce	pages 8-11

Executive Summary

Australia's 2.7 million family and friend carers are an integral part of the nation's health system and are the foundation of our aged, disability and community care systems. Access Economics estimated in 2015 that carers provided 1.9 billion hours of unpaid care and that the annual cost of replacing this care with formal care services amounted to \$60.3 billion.

Carers Australia acknowledges the government's clear appreciation of the vital contribution of family and friend carers and its recognition that carers both deserve and need support in their own right to sustain that contribution.

In particular, Carers Australia greatly appreciates the funding made available over three years for the Young Carer Bursary Programme. The applications we have received from young carers to date have vividly illustrated the extreme level of socio-economic disadvantage so many contend with on top of the heavy care-load they carry. The gratitude of successful applicants and their description of the difference the bursary will make to their capacity to remain engaged in education and improve performance when some of their financial difficulties are addressed has been very moving. However these young carers' stories have also highlighted that they, like other carers, have many other needs which should be addressed. These needs are addressed in Recommendation 2.

A further manifestation of the government's commitment to assisting carers is the launching of the new Carer Gateway, which is to be followed by the development of an Integrated Plan for Carer Support Services.

This submission is primarily focused on recommendations to improve carer support services within the context of these developments. These include allowing sufficient time and consultation to design new integrated carer support services. We suggest that this new service landscape should include an individualised, long-term approach to supporting carers with multiple disadvantages.

We also recommend relaxation of regulations which substantially prevent carers from acquiring education and training, unpaid voluntary work and other work experience while on Carer Payment, and we recommend enhanced assistance to carers facing challenges in transitioning from a caring role into the workforce after a prolonged period of caring.

Recommendations

1. Recommendations in relation to the implementation of the new Integrated Carer Support Model

- **While redesign of the service landscape is likely to provide some efficiencies, it is likely that additional funding will need to be provided for carer support services in anticipation of an increase in demand arising from heightened carer awareness as a result of the Carer Gateway.**
- **The design of the new carer support landscape should not be rushed. As was the case with aged care reform, sufficient time should be allowed to explore the design elements of the**

new landscape, how these design elements will play out in practice and what transition arrangements need to be in place to minimise disruption to existing supports.

- Carers, their associations and service providers should be extensively involved in the design elements of the project as it evolves.
- Existing carer support funding through a variety of programmes should be maintained until such time as the Integrated Carer Support model has been identified and is ready for implementation – at this stage anticipated to be July 2018.

2. Recommendation in relation to support for carers with complex needs

- Carers Australia recommends the development and funding of a dedicated programme to provide wrap-around supports for all carers with multiple and complex needs. While this might be a component of the final design of the Integrated Carer Support Model, Carers Australia recommends that the Government pilots such a programme in the interim with a view to establishing its effectiveness.
- Introduce and fund a sub-program under the broader proposed complex needs programme to support young carers facing multiple disadvantages. The programme should incorporate a family-oriented case management approach with a focus on early intervention and wrap-around support services to reduce specific stressors confronting young carers and improve their life chances.

3. Recommendation to assist long term carers to transition into work

- The *Guide to Social Security Law* should provide that a temporary cessation of constant care due to participation in paid employment, unpaid voluntary work, education or training that exceeds 25 hours per week:
 - (a) does not automatically result in review of the Carer Payment; and
 - (b) may, in some circumstances, be compatible with the constant care requirement for qualification for Carer Payment.
- That, at a minimum, the Job Seeker Classification Instrument (JSCI) be amended to give proper weighting to the impact of former and current caring responsibilities in determining the stream of support that carers who find themselves in a position to pursue employment opportunities and former carers require to have a reasonable prospect of finding sustainable employment.
- That the government explore a dedicated programme to assist carers into paid work once their caring role has diminished or ceased. Such a programme could be based on the model currently being developed for disability employment services and would include assistance to become job-ready and to pay a fee to the employment provider of their choice as an incentive for finding them suitable, sustainable employment.

DISCUSSION OF ISSUES AND RECOMMENDATIONS

1. Integrating and aligning general support services for carers

In the 2015-16 Federal Budget the Government provided \$33.7 million over four years to create a national gateway for all carers to heighten carer self-identification and general awareness of available support services.

The next step is to develop an Integrated Plan for Carer Support Services (the Plan)¹; something which Carers Australia has been advocating for many years now based on numerous international evaluations of different models for delivering services to carers and on our own experience of delivering such supports.

Carers Australia's view is that the delivery of integrated carer supports should be broadly in line with the directions identified in the 2011 Productivity Commission report on *Caring for Older Australians*.

These directions can be summarised in the following principles.

- The existing suite of supports available to carers be maintained (but in some cases improved and expanded).
- Carer support services are most effective when harmonised and streamlined. This means:
 - Where they can be coordinated substantially through a carer support centre;
 - While supports for carers must be individualised, there should be no division which distorts access to and delivery of carer supports based on artificial structural distinctions, such as the age, disability or illness of the person being cared for. (This point has gathered weight since the access to support and services for carers of people who are over 65 and carers of people who are under 65 have become fragmented as result of the introduction of the new aged care reforms and the NDIS. The different entitlements to carer support under these two systems presents particular difficulties for sandwich carers – i.e., those who care for both an older person and someone with a disability, mental illness or chronic illness under the age of 65.)

The Productivity Commission identified the suite of services which should be provided through carer support centres. These included (at a minimum):

- assessments of carers' needs through carer support centres;
- carer education and training (information about what to expect on the carer journey and practical advice and training on key caring tasks and challenges);
- emergency respite;
- carer counselling;
- peer group support options for carers;

¹ <https://www.dss.gov.au/disability-and-carers/news/2015/carers-support-services-national-carer-gateway>

- advocacy assistance.²

The redesign of the carer services landscape is currently scheduled to be undertaken in 2016 with roll-out anticipated in July 2018 (allowing time for the sector to transition between the finalisation of the new service landscape and implementation). We are strongly of the view that this is the minimum amount of time in which a well-thought through and sustainable reform of carer services can be completed.

1. Recommendations in relation to the implementation of the new Integrated Carer Support Model

- **While redesign of the service landscape is likely to provide some efficiencies, it is likely that additional funding will need to be provided for carer support services in anticipation of an increase in demand arising from heightened carer awareness as a result of the Carer Gateway.**
- **The design of the new carer support landscape should not be rushed. As was the case with aged care reform, sufficient time should be allowed to explore the design elements of the new landscape, how these design elements will play out in practice and what transition arrangements need to be in place to minimise disruption to existing supports.**
- **Carers, their associations and service providers should be extensively involved in the design elements of the project as it evolves.**
- **Existing carer support funding through a variety of programmes should be maintained until such time as the Integrated Carer Support model has been identified and is ready for implementation – at this stage anticipated to be July 2018.**

2. Wrap-around support for carers with complex needs

In addition to fostering streamlined, flexible and easy to navigate access to carer support services, Carers Australia is of the view that a special programme needs to be developed for carers with complex needs.

Many carers need a coordinated range of supports to help them address the multiple problems they are encountering. These problems might include severe financial stress, caring for someone with challenging behaviours, their own poor health and mental stress, exhaustion, social isolation, and poor knowledge of services available (including mainstream and specialist services) both for themselves and those they care for.

² Productivity Commission, *Caring For Older Australians*, 28 June 2011, Recommendation 13.1

In this context it is worth noting that, of Australia's 770,000 primary carers:

- 39% spend on average 40 hours or more caring every week
- 60% are not employed and social security is the main source of income for 55%
- 37% have a disability of some kind
- 38% report that their physical or emotional wellbeing has changed due to their caring role
- 10% plus have been diagnosed with a stress related illness due to their caring role
- many are socially isolated as a result of their caring role
- 21% care for more than one who person with a disability, chronic illness, mental illness or who are frail aged.³

Others experience special disadvantages associated with their demographic status such as young carers, Aboriginal and Torres Strait Islander carers, and carers from some CALD backgrounds.

Getting help in relation to only one or two of these circumstances and having to organise these supports from different parts of government (including national, state and territory, and local governments) and from different parts of the health and community sectors is likely to provide only partial or temporary relief. They need help to address their long-term situation and reduce a range of disadvantages in order to prevent them from continuing to fall into crisis, to live beyond the day-to-day situation and to help them plan a future for themselves and those they care for. They need experienced case workers to organise a support plan and who can be re-accessed when these plans go awry.

In short - just as wrap-around and coordinated models of support which incorporate early intervention and long-term planning have been adopted as best practice for people with high needs across the recent and proposed aged care, disability and mental health reforms – a similar model needs to be developed and funded in the carer space.

Young carers with complex needs – a special case

Young carers are people up to 25 years of age who care in families where one or more person has an illness, a disability, a mental health issue or who has an alcohol or other drug problem. According to the 2012 ABS Survey on Disability, Ageing and Carers (SDAC), 231,200 carers were aged between 15-24 and 74,800 carers were aged less than 15 years. The majority of young carers are the son or daughter of the person they provide care to, though they can also care for siblings, grandparents, partners, their own children, other relatives, or a friends.⁴

The extent to which young carers are challenged by their caring role varies. However many young carers have substantial caring responsibilities combined with a range of economic, health and social disadvantages.

³ Australian Bureau of Statistics (2012). Survey of Disability, Ageing and Carers 2012. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

⁴ Australian Bureau of Statistics (2012). Survey of Disability, Ageing and Carers 2012. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

For example:

- They are frequently in single parent families.
- They often feel they have no choice but to take on family responsibilities that no child or even young adult should really have to deal with.
- The task of combining care (both for someone with a disability and other family members), plus education and sometimes casual work to support the family income is extraordinarily challenging.
- Their education is often impacted which reduces their future life chances.
- Carers aged 15 to 24 are almost twice as likely to be unemployed than other 15 to 24 year olds who do not have a caring role (20.0% and 11.6%, respectively).
- They tend to be particularly socially isolated because they can't do the things their peers do and they are considered in some ways "different" by their peers.
- They need a lot of support; including help at home, respite from caring (particularly when educational pressures are greatest – such as exam times), connection with other young carers to reduce their social isolation, assistance with educational needs such as tutoring and the resources they need to engage in education.
- They may also need counselling to assist them to cope with anxiety and depression.
- They are not a specific target group for mainstream youth services.
- They also need assistance to plan a future beyond caring.

General supports available under the Young Carer Respite and Information Services (YCRIS) Programme do include some direct and indirect respite, peer support, skill development (e.g. cooking, budgeting), referral to counselling, some assistance with education and holiday camps and other recreational activities. Such assistance offers clear benefits to young carers. However there remains a need to offer more intensive, ongoing packaged support to young carers and their families who are confronted with very complex needs.

These young carers require both early intervention and expert guidance and a range of supports to minimise the impact caring has on their short-term wellbeing and long-term life chances.

Case Study

- *Alex* is the young carer of a parent with a debilitating musculoskeletal chronic illness, depression and anxiety.*
- *It is a single parent, low income family.*
- *There is a previous history of family domestic violence.*
- *She has no family close by and a reduced circle of friends.*
- *She assists with domestic tasks and provides emotional support and is involved in all decision-making affecting the household.*
- *She also acts in a parental role to younger sibling with PTSD.*
- *Alex has her own health and stress issues.*
- *The educational performance of both Alex and her sibling has been affected by compounding circumstances surrounding their family.*

*Name has been changed

In particular, there is a need for a 'whole of family' approach to case management which addresses the dynamics of the home and caring environment, including the age appropriateness of the care required and the identification of other options. There is also a need for early intervention before young carers and their families fall into crisis.

A number of associations in the Carers Australia Network do what they can within current funding constraints to provide this kind of assistance. However it is a labour intensive effort which may require: discussions with the young carers' families; identification of services available (either to the person being cared for or to the young carer); assistance with education; identification of peer support groups and activities; and sometimes liaison with multiple agencies such as schools, adult mental health services, youth justice, and other community organisations. Resources to undertake this kind of work are scarce and intensive intervention can often only be offered in crisis situations. It is also very difficult to provide on-going case management which will prevent the family from falling into crisis again.

In this context it is worth noting that young carer programmes with similar design elements, such as the Young Carer Pathfinders Programme in the UK, have been extensively evaluated and showed cost savings to areas such as youth justice, child safety, health and welfare (disability, mental health, drug and alcohol, domestic violence, sexual health) and education and employment".⁵

Recommendation in relation to support for carers with complex needs

- **Carers Australia recommends the development and funding of a dedicated programme to provide wrap-around supports for all carers with multiple and complex needs. While this might be a component of the final design of the Integrated Carer Support Model, Carers Australia recommends that the Government pilots such a programme in the interim with a view to establishing its effectiveness.**
- **Introduce and fund a sub-program under the broader proposed complex needs programme to support young carers facing multiple disadvantages. The programme should incorporate a family-oriented case management approach with a focus on early intervention and wrap-around support services to reduce specific stressors confronting young carers and improve their life chances.**

⁵ York Consulting, Turning around the lives of families with multiple problems - an evaluation of the Family and Young Carer Pathfinders Programme", 2010 (Commissioned by the UK Department for Education), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/182428/DFE-RR154.pdf

3. Assisting carers and former carers to transition to the workforce

Long-term carers have particular difficulties entering or re-entering the workforce once their caring role ceases, as they are often left with little relevant employment experience or current marketable skills. Indeed, according to the ABS 2012 Survey of Disability, Ageing and Carers (SDAC), over 27% of primary carers had been caring for between 5 and 9 years, 27% had been carers for between 10 and 24 years, and 7% had been carers for 25 years or more⁶.

Carers who have previously received the Carer Payment will often transition onto Newstart Allowance when the person they care for dies or moves into residential care, or when the carer is able for other reasons to reduce the hours of care. Indeed, the McClure review of *A New System for Better Employment and Social Outcomes* commented that over 63% of carers who exit from Carer Payment before Age Pension age transition to another form of income support such as Newstart Allowance. Two out of three individuals receiving the Carer Payment in 2011 remained on income support three years later.⁷ Some remain on income support for the rest of their lives.

There are a range of initiatives which could assist long-term carers to resume employment when their caring responsibilities allow them to do so.

Some involve providing greater opportunities and incentives to assist carers to acquire skills and work experience while they are in a substantial caring role. Others are directed to assisting them to find employment once their caring role has ceased or is significantly diminished.

Work related opportunities while caring

To qualify for Carer Payment under the *Social Security Act (1991)* a person must be providing another person (or persons) with 'constant care' which is defined in the administrative guidelines as: "Personally provides care on a daily basis for a 'significant period' during each day" providing "at least the equivalent of a normal working day in personal care...This includes circumstances where the carer or care receiver are absent from the care situation for part of the day, but the intensity of the care provided during the remainder of any 24 hour period is such that it roughly equates to a normal working day."⁸

However there is a policy rule under the Department of Social Services guidelines which requires the Carer Payment recipient to have their qualification reviewed if they 'cease to care' for more than 25 hours a week. Ceasing to care includes hours taken to participate in education and training, volunteering and any hours of paid work, including any travelling time associated with these activities.⁹

⁶ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC), 2012

⁷ Report of the Reference Group on Welfare Reform to the Minister for Social Services *A New System for Better Employment and Social Outcomes*, February 2015, p.54

⁸ Australian Government, Guide to Social Security Law, Version 1.213 2015, Carer Payment (CP) – Description, <http://guides.dss.gov.au/guide-social-security-law/1/1/c/310>

⁹ Australian Government, Guide to Social Security Law, 3.6.4.70, *Changes to Carer Situation – Effect on CP Qualification* <http://guides.dss.gov.au/guide-social-security-law/3/6/4/70>

This rule acts as a disincentive for those carers who may, from time to time, be able to arrange non-ongoing replacement care which would assist them to retain some attachment to working environments and/or education but who are reluctant to take advantage of these opportunities if it means having to go through a review process on each occasion.

In 2013 the Australian Law Reform Commission recommended that the *Guide to Social Security Law* should provide that a temporary cessation of constant care due to participation in paid employment, unpaid voluntary work, education or training that exceeds 25 hours per week:

- does not result in automatic cancellation of Carer Payment; and
- may, in some circumstances, be compatible with the constant care requirement for qualification for Carer Payment.¹⁰

In addition, the McClure review of *A New System for Better Employment and Social Outcomes* recommended: “Support initiatives to grow the rate of volunteering as an avenue for social and economic participation, in particular for jobseekers, carers and people with a partial capacity to work.”¹¹

Eligibility for Carer Payment should focus on the actual level of care provided per week rather than the use of a cap on the number of hours of study or training that are undertaken in addition to caring responsibilities. This would allow carers to engage in education and training whilst caring, thus increasing their chances of moving back into the workforce when their caring role ceases, and reducing their future reliance on income support.

¹⁰ Australian Law Reform Commission 2013, *Access All Ages: Older Workers & Commonwealth Laws*, 176

¹¹ Report of the Reference Group on Welfare Reform to the Minister for Social Services *A New System for Better Employment and Social Outcomes*, February 2015, p.51

Employment assistance for former carers or carers whose caring responsibilities have diminished

Case Study:

I was a carer for 17½ years.

My mother suffered a stroke and was in a wheelchair, paralysed on the right side, and could not speak.

My father became very ill with a heart condition and he passed away in 1995. I worked for another year, with some assistance to look after my mum in our family home. My sister suffered a stroke so I left work in 1996 and went on the Carer Payment full time. I cared for mum until she passed away. When mum passed away I had the three months bereavement time and went to Centrelink. In my first contact with them after that I had to tell them I was a carer; they just thought I was a Newstart person.

It is like you fall through the cracks and you don't fit any existing category after being a carer and on the carer payment, so you are not recognised as being a carer and you are just a Newstart person that was a carer.

Recipients of Newstart who have Mutual Obligation Requirements must have a Job Plan which outlines the activities they agree to undertake while looking for work. As part of this process, most recipients are referred by Centrelink to a 'jobactive' provider, who uses the Job Seeker Classification Instrument (JSCI) to measure a job seeker's relative difficulty in gaining and maintaining employment and to identify what level of support the job seeker will need to help them find work. Job seekers are then placed in different Streams according to their needs, with Stream A for the most 'work ready job seekers' to Stream C for those with multiple and complex needs.

The Job Seeker Classification Instrument (JSCI) does not currently specifically seek to assess the impact of caring for an adult with a disability, a chronic illness, a mental health disorder or illness or someone who is frail aged. It should include an appropriate weighting for caring responsibilities (other than just caring for a child up to 15 years) and job seekers should be specifically asked if they have or have had such responsibilities.

Other options for assisting carers to find employment

Carers Australia believes there would be merit in developing a special programme to assist long-term carers to transition into the workforce which would embrace some of the design elements currently being considered for the new Disability Employment Framework. Such a programme would provide former carers with assistance in identifying their skills (including skills developed through their caring role), training in writing job applications and interview skills, and funding to pay employment providers

to assist them to find suitable, sustainable work. The funding should be allocated to the carer to choose between employment providers rather than allocated directly to providers.

3. Recommendation to assist long term carers to transition into work

- **The *Guide to Social Security Law* should provide that a temporary cessation of constant care due to participation in paid employment, unpaid voluntary work, education or training that exceeds 25 hours per week:
 - (a) does not automatically result in review of the Carer Payment; and
 - (b) may, in some circumstances, be compatible with the constant care requirement for qualification for Carer Payment.**
- **That, at a minimum, the Job Seeker Classification Instrument (JSCI) be amended to give proper weighting to the impact of former and current caring responsibilities in determining the stream of support that carers who find themselves in a position to pursue employment opportunities and former carers require to have a reasonable prospect of finding sustainable employment.**
- **That the government explore a dedicated programme to assist carers into paid work once their caring role has diminished or ceased. Such a programme could be based on the model currently being developed for disability employment services and would include assistance to become job-ready and to pay a fee to the employment provider of their choice as an incentive for finding them suitable, sustainable employment.**