



Federal Budget Submission 2014–15

Unpaid Carers: the necessary investment

December 2013

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

Australia's 2.7 million family and friend carers are an integral part of Australia's health system and are the foundation of our aged, disability and community care systems. Access Economics estimated in 2010 that carers provided 1.32 billion hours of unpaid care each year and that it would cost \$40.9 billion per annum to the Australian economy to replace their care with formal care services.

Carers Australia acknowledges the government's clear appreciation of the vital contribution of family and friend carers to those they care for and to keeping the cost of the nation's aged, disability and community care services affordable. We also welcome the recognition that carers both deserve and need support to sustain that contribution.

This submission focuses on the continuing need to provide suitable, accessible support to carers to improve their resilience and sustain their caring role. It also recommends regulatory changes and employment assistance to encourage and enable long-term carers to return to work once their caring role has ended or has been significantly reduced.

Recommendation 1:

- That it is understood that the National Disability Insurance Scheme (NDIS) does not replace necessary support services made available through current carer support programs and that the funding of those programs will need to be maintained and increased in line with the growth of the unpaid carer population.
- That the carers of people with a disability who are NDIS package recipients continue to have access to respite services outside the NDIS where:
 - those services cannot be provided within the NDIS because of the constrained nature of NDIS respite; and where
 - NDIS participants do not include respite for their carers as part of their Individual Support Packages.

Recommendation 2:

- Financial investment in the 2013-14 Federal Budget directed toward changing the balance between supported community aged care and high cost residential aged care should not be decreased. Changes which will benefit both carers and those they care for include the expansion of Home Care Packages based on the Consumer Directed Care (CDC) model and a more integrated and flexible Home Support Program.
- Implementation deadlines of the former government's aged care reform agenda should be revisited to ensure proper planning and the effective implementation of each reform, including the introduction of new Carer Support Centres.

Recommendation 3:

Carers Australia endorses the recommendations of Alzheimer's Australia's 2014-15 pre-Budget Submission to better support the carers of people with dementia through:

- Investing \$15.5 million a year to develop dementia specific respite services that would receive a 10% dementia supplement in line with the dementia supplement provided for community care

packages. This supplement would be linked to a requirement for ongoing dementia training for staff.

- Conducting a cost-neutral trial to evaluate the costs and benefits of allowing consumers to cash out the value of respite services to enable them to purchase the services they need.
- Developing innovative models of planned dementia-specific residential respite services within the current funding system which would be available for longer term stays in order to support people to continue living in the community for longer periods of time and to assist with transitions to residential care.
- The current financial resourcing for the Dementia and Behaviour Management Advisory Service (DBMAS) to be doubled over the next three years to ensure that the service can adequately support family carers, residential, primary and acute care.

Recommendation 4:

- Changes to be made to the design and wording of the application forms for Carer Allowance and Carer Payment to better capture the mental health caring role. This will require changes to the Adult Disability Assessment Tool, the disallowable instrument that underpins the content of the forms.
- Centrelink staff should receive training that includes specific information about the nature, value and impacts of caring for a person with a mental illness.

Recommendation 5:

- Introduction of a new temporary exemption category from the Newstart Allowance participation requirements for carers whose care recipient has died or who continue to provide substantial support when the person they have cared for is transferred to an institutional environment.

Recommendation 6:

- Review the application of inflexible Social Security Act rules which limit the ability of Carer Payment recipients to participate in education and training while they are in a caring role.

Recommendation 7:

- The Job Seeker Classification Instrument (JSCI) should include specific questions that will identify carers.
- Jobseekers who are identified as long term carers should receive more intensive support, including a minimum of Stream 2 assistance through Job Services Australia (JSA) as soon as they enter the Job Services Australia system.
- All carers who are transitioning from Carer Payment to employment should have access to retraining through their job service provider and be informed of their right to retraining funding.

Background on family and friend carers

The social and economic significance of family and friend carers

- Carers are an integral part of Australia's health system and are the foundation of our aged, disability and community care systems. Access Economics estimated in 2010 that carers provided 1.32 billion hours of unpaid care each year and that it would cost \$40.9 billion per annum to the Australian economy to replace their care with formal care services.

How many family and friend carers are there?

- According to the latest 2012 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), there are 2.7 million family and friend carers over the age of 15 in Australia (or 11.9% of the population).
- 770,000 of Australia's carers are primary carers (those who provide the majority of informal assistance with the activities of daily living to a person with disability with one or more of the core activities of mobility, self-care and communication).
- Of these primary carers, 51% provided care to a person over the age of 65 (many of whom had a profound/severe core activity limitation). Forty nine percent provided care to someone under the age of 65.

Hours of care provided

- On average, about 40% of primary carers provide 40 or more hours per week of unpaid care.

Physical and mental impacts of caring

- The negative impacts of caring have been documented in the Australian Unity Wellbeing Index Survey, commissioned by Carers Australia and conducted by Deakin University in 2007. The survey revealed that carers had the lowest collective wellbeing of any population group investigated up to that point by the researchers. Above average stress and depression and experience of chronic pain contributed to this finding, as did social isolation.
- According to the 2012 ABS Survey of Disability, Ageing and Carers (SDAC), primary carers were significantly more likely to have a disability themselves – more than one third of primary carers having a disability (37%), compared with 16% of people who were not in a caring role.

Carers are financially challenged

- In 2012, almost two thirds (65%) of primary carers resided in a household with equivalised gross household income in the lowest two quintiles, compared with 36% of non-carers.
- 55% of primary carers are on a Government pension or allowance. Fifty four per cent of primary carers have difficulty meeting everyday costs as a result of a caring role.

ISSUES AND RECOMMENDATIONS

Support Services for Carers

Issue 1: Maintaining and Improving Carer Support Services

- The combined negative impacts of caring listed above illustrate that carers frequently need funded support services in order to sustain the caring role. At the national level these supports are provided through a range of government programs under the Department of Social Services. These include information and referral services, counselling and respite programs. These services are available to carers of people with a physical impairment or mental health condition, the chronically ill and the frail aged.
- It is important to understand that the National Disability Insurance Scheme (NDIS) does not replace the need for carer specific support services to be maintained.
 - The National Disability Insurance Scheme will not cover everyone with a disability. It will not cover all people with chronic illnesses, drug and alcohol problems, any disabilities which are not considered permanent (but which may still require substantial contributions from carers over long periods of time) or anyone over the age of 65 unless they were participants of NDIS before they reached that age. In this context it is notable that NDIS packaged support is expected to cover 460,000 people when fully rolled out. The 2012 ABS Survey of Disability, Ageing and Carers (SDAC) estimated that 4.2 million Australians, or 18.5% of the population, had a disability restricting everyday activities and of these 1.4 million had a severe or profound core activity limitation.¹
 - National Disability Insurance Scheme (NDIS) Individual Support Packages are for people with a disability to achieve their goals and aspirations, not their carers. These packages won't necessarily involve replacing unpaid carer with paid care and, in the majority of cases, unpaid carers will continue to provide the support they do now. While some funding from existing carers support programs (the Mental Health Respite Program and Young Carers Respite and Information Services Program) is being made available for respite under the NDIS, the type of respite available is of a limited nature and must be requested by the person with a disability as part of their package.
- Under these circumstances, there remains a pressing need to maintain funding to carer specific support programs which will need to be accessed both by carers of recipients of NDIS packages and carers of people with disabilities and chronic medical and/or mental health conditions who are not covered by the NDIS. These supports include information, referral, counselling, training, respite and home help.

¹ Australian Bureau of Statistics, 2012 *Survey of Disability Ageing and Carers*

Recommendation 1:

- **That it is understood that the NDIS does not replace necessary support services made available through current carer support programs and that the funding of those programs will need to be maintained and increased in line with the growth of the unpaid carer population.**
- **That the carers of people with a disability who are NDIS package recipients continue to have access to respite services outside the NDIS where they cannot be provided within the NDIS because of the constrained nature of NDIS respite and where package recipients do not include respite for their carers as part of their packages.**

Issue 2: Aged Care reform

- As noted in the Productivity Commission's 2011 inquiry into *Caring for Older Australians* and its recent report on *An Ageing Australia: Preparing for the Future*, the growth rate of the oldest segments of the population is accelerating, bringing with it serious impacts on the affordability of aged care. It is clearly in the interests of the economy for people to age at home for as long as possible rather than transferring into expensive residential care. Their capacity to do so will depend on providing adequate supports to sustain the role of family and friend carers.
- The previous Government's *Living Longer, Living Better* package adopted many of the recommendations of the Productivity Commission's 2011 inquiry into *Caring for Older Australians*. However, in the view of Carers Australia the overly-short implementation deadlines threatened to undermine proper planning and ran the risk of causing counter-productive disruption to older people and their carers and families.
- Among the former *Living Longer, Living Better* reforms which Carers Australia believes will assist carers to continue to provide support for the frail aged are the following:
 - More than 80,000 additional Home Care Packages (organised into four levels of required support) to be made available over 10 years to 2021-22 and to be offered on a Consumer Directed Care (CDC) basis. Existing packages will transition to CDC by 1 July 2015.
 - The integration of a range of fragmented, restrictive home support programs (Home and Community Care [HACC], National Respite for Carers Program [NRCP], Day Therapy Centres [DTC] and Assistance with Care and Housing for the Aged [ACHA] into a single Commonwealth Home Support Program and subsequent growth of this funding stream. This includes integrated, adequately funded respite options which will allow carers to access respite or rest periods in the form they need and at the time they need them.
- Under the *Living Longer, Living Better* reforms new Carer Support Centres were to be established under the auspices and funding of the Health and Ageing portfolio. These centres would replace existing Commonwealth Respite and Carelink Centres (CRCCs). While Carers Australia supports the establishment of better designed and better funded Carer Support Centres, it is important for

reasons of efficacy and of economies of scope and scale that these new centres support all carers regardless of the age of the person they are caring for. It is also important that there should not be a rush to establish such centres until the interfaces between carer supports across the full range of Government programs have been carefully thought through. Planning for the new Carer Support Centres requires adequate opportunity for proper public consultation and adequate time for the sector to adjust to the new program structure.

Recommendation 2:

- **Financial investment in the 2013-14 Federal Budget directed to changing the balance between supported community aged care and high cost residential aged care should not be decreased. Changes which will benefit both carers and those they care for include the expansion of Home Care Packages based on the Consumer Directed Care (CDC) model and a more integrated and flexible Home Support Program.**
- **Implementation deadlines of the former government's aged care reform agenda should be revisited to ensure proper planning and effective implementation of each reform, including the introduction of new Carer Support Centres.**

Issue 3: Improved support for carers of people with dementia

- Access to respite (the ability to take a break from caring) is of particular significance to the carers of people with dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD). These carers both express a stronger need for respite and access respite services significantly more often than most other categories of carers.²
- The high need for respite among carers of people with dementia is partly a reflection of the time and effort invested by these carers. Primary carers of people with dementia generally put in significantly more hours of caring than the average for all primary carers (81.2% of carers of people with dementia put in 40 or more hours of care per week compared to 41.5% of all primary carers).³
- Some forms of respite are considerably more popular amongst people with dementia and their carers than others. In 2012, the Dementia Collaborative Research Centre reported that aged care residential respite care (or respite provided in nursing homes) "generated the most complaints among the carers surveyed" - partly because providers are reluctant to take on people with challenging behavioural symptoms for short term stays and partly because institutional environments can be frightening and confusing for people with dementia.⁴
- Other short-term respite options (many of which are not widely available) usually better suit the needs of carers and those they care for. These include:

² Australian Institute of Health and Welfare, 2012, *Dementia in Australia*, page 102

³ Australian Institute of Health and Welfare, 2012, *Dementia in Australia*, table 5.12

⁴ Dementia Collaborative Research Centre: Summary of "Respite Care in Dementia: Carer Perspectives." Report on Full Study, (March 2012), no page number.

- Day centre based respite, where the person cared for has an opportunity to socialise and engage in appropriate activities.
 - Day care and overnight respite in homelike community housing, for example respite cottages.
 - In-home respite, where a paid carer comes to the home of the person with dementia for a period of time. This is particularly popular with carers of people with dementia as it means that the person they care for can remain in a familiar environment.
 - Commonwealth Respite and Carelink Centres also arrange short breaks (1-2 nights away) for both the carer and the person receiving care in holiday facilities which can accommodate people with various disabilities. They are accompanied by paid carer support workers.
 - Respite provided in the home of a qualified paid carer (not unlike home-based child care).
- Carers of people with dementia also complain about the lack of information about the management of people with BPSD and about the availability of carer support. Because the efforts to inform dementia carers about the existence of respite options are not systematic, some fall through the gaps or stumble across this type of support by chance. The Dementia and Behaviour Management Advisory Service (DBMAS) programs improve the capacity of family carers, care workers, and service providers to respond to BPSD. DBMAS programs include provision of information and advice, undertaking assessments and case management, and the delivery of tailored information and education (including to Aboriginal and Torres Strait Islander communities). However, with the growth in the number of people being diagnosed with dementia, the current funding for this program is under strain.

Recommendation 3:

Carers Australia supports the recommendations of Alzheimer’s Australia 2014-15 pre-Budget Submission to better support the carers of people with dementia through:

- **Investing \$15.5 million a year to develop dementia specific respite services that would receive a 10% dementia supplement in line with the dementia supplement provided for community care packages. This supplement would be linked to a requirement for ongoing dementia training for staff.**
- **Conducting a cost-neutral trial to evaluate the costs and benefits of allowing consumers to cash out the value of respite services to enable them to purchase the services they need**
- **Developing innovative models of planned dementia specific residential respite services within the current funding system which would be available for longer term stays in order to support people to continue living in the community for longer periods of time and to assist with transitions to residential care.**
- **The current financial resourcing for DBMAS to be doubled over the next three years to ensure that the service can adequately support family carers, residential, primary and acute care.**

More Effective and Efficient Access to Income Support for Carers

Issue 4: Mental Health Carers

- Carers of people with mental illness experience significant economic disadvantage. A Victorian survey revealed that 64% of surveyed mental health carers were unable to pay their utility bills on time, 32% were unable to heat or cool their homes, and 26% went without meals in the previous 12 months.⁵
- Carers who are providing significant levels of care for people with mental illness are faced with many barriers to accessing vital financial support through the Carer Payment and Carer Allowance.
- The Adult Disability Assessment Tool (ADAT) used to determine the functioning of the person receiving care does not take into account the symptoms of psychosis (such as hallucinations or delusions) or the cognitive problems associated with long-term mental illness such as decision-making difficulties. Research undertaken by Carers Victoria into the experiences of mental health carers accessing income support also found that Centrelink staff often have a poor understanding of the challenges faced by carers of people with mental illness, which in turn lead some staff to be dismissive and at times disrespectful of those carers.
- With a limited mental health budget and high demand for access to mental health services, sustaining and recognising the role of mental health carers should be very high priority.

Recommendation 4:

- **Changes to be made to the design and wording of the application forms for Carer Allowance and Carer Payment to better capture the mental health caring role. This will require changes to the Adult Disability Assessment Tool, the disallowable instrument that underpins the content of the forms.**
- **Centrelink staff should receive training that includes specific information about the nature, value and impacts of caring for a person with a mental illness.**

Issue 5: Transitioning from Carer Payment to Newstart Allowance

- 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. Carers who have been relying on the Carer Payment plus perhaps a disability payment or pension for the person they have been caring for will experience a significant drop in household income once they have

⁵ Carers Victoria 2013, *Invisible Care- Access to Carer Payment and Carer Allowance by Victorian carers of a person with a mental illness*, pp.15-16

transitioned to Newstart.⁶ This may require finding new accommodation and downsizing their household and expenditure, in addition to dealing with complex legal and financial arrangements. At the same time they will be adjusting to grief and loss. If the person they care for has been transferred to institutional care, many if not most carers visit daily to assist with their adjustment.

- With over 59 per cent of carers surveyed having been in their caring role for between 5 and 25 years or more⁷, the transition to Newstart can be extremely difficult both financially and emotionally. Many of these carers will not be ready to become active jobseekers as soon as they become Newstart recipients. Enforcing compulsory participation requirements on these carers (such as interviews with Job Services Australia providers) before they are ready is not only distressing for the carers, but is a waste of government resources in the JSA program.

Recommendation 5:

- **Introduction of a new temporary exemption category from the Newstart Allowance participation requirements for carers whose care recipient has died or who continue to provide substantial support when the person they have cared for is transferred to an institutional environment.**

Increasing Workforce Participation of Carers

With longer life expectancy and a burgeoning ageing population, Australia is facing the dual task of increasing both its labour supply and the number of informal carers. In 2007 there were 5 people of working age in Australia to support every person aged 65 and over. By 2047 it is estimated there will only be 2.4 people⁸.

It is estimated that a 3% increase in participation among workers aged 55 and over would result in a \$33 billion boost to GDP – or around 1.6% of national income.⁹ With over 500,000 carers between the ages of 55-64 years, any efforts to increase employment among this cohort must consider the barriers faced by carers entering or re-entering the workforce.

Issue 6: Education and Training Restrictions while receiving Carer Payment; the ‘25 hour’ rule

- 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...”

⁶ Carers Australia 2012, ‘Submission to the Senate Education, Employment and Workplace Relations References Committee *Inquiry into the adequacy of the allowance payment system for jobseekers and others, the appropriateness of the allowance payment system as a support into work and the impact of the changing nature of the labour market*’, pp.20-21

⁷ Australian Bureau of Statistics, 2009 *Survey of Disability Ageing and Carers*

⁸ Australian Government, 2007, *Intergenerational Report*, p.17

⁹ Deloitte Access Economics, 2012, *Increasing participation among older workers: The grey army advances*, p.i

“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.”¹⁰

- However, under the Department of Social Services guidelines is a policy rule in which the Carer Payment recipient has their qualification reviewed if they ‘cease to care’ for more than 25 hours a week.¹¹ This ‘25 hour rule’ unnecessarily restricts the capacity of carers to prepare for when their caring role will cease by limiting their ability to undertake education and training while caring. Considering the strong association between higher educational attainment and subsequent labour participation rates (with education having its biggest relative impacts on participation rates at the oldest ages¹²), it is not surprising that employment rates among carers remain low. Only 53.6% of primary carers aged 15-64 years are employed compared to 79.4% of non-carers of the same age.¹³
- Furthermore, evidence shows that people who exit from the labour market onto income support often remain on this payment or another form of income support for the remainder of their lives¹⁴. Indeed 70.6% of young carers who had received the Carer Payment or Carer Allowance remained on income support after completing care.¹⁵
- Eligibility for Carer Payment should therefore 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 (both young and of working age) 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.

Recommendation 6:

Review the application of inflexible Social Security Act rules which limit the ability of Carer Payment recipients to participate in education and training while they are in a caring role.

Issue 7: Better support for carers through Job Services Australia

- 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 no longer able to keep providing care. Estimates show there are some 78,000 carers who receive an income support payment, with around 18,000 on Newstart.¹⁶

¹⁰ Australian Government, 2011 ‘Guide to the *Social Security Act 1999* 1.1.C.310 Constant Care (CP) available at http://www.facs.gov.au/guides_acts/ssg/ssguide-1/ssguide-1.1/ssguide-1.1.c/ssguide-1.1.c.310.html .

¹¹ Australian Government, 2011 ‘Guide to the *Social Security Act 1991* 3.6.4.70 Changes to Carer Situation- Effect on CP Qualifications’ available at http://www.facs.gov.au/guides_acts/ssg/ssguide-3/ssguide-3.6/ssguide-3.6.4/ssguide-3.6.4.70.html .

¹² Productivity Commission 2013, *An Ageing Australia: Preparing for the Future*, pp.70-71

¹³ COAG Reform Council, 2012, *Disability 2010-11: Comparing performance across Australia*, Report to the Council of Australian Governments

¹⁴ Productivity Commission 2013, *An Ageing Australia: Preparing for the Future*, P.78

¹⁵ Bray, JR 2012, *Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes*, p.108

¹⁶ 2009 Household, Income and Labour Dynamics in Australia (HILDA) Survey

- All recipients of Newstart have to have an Employment Pathway 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 Job Services Australia 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 need, with Stream 1 for 'work ready job seekers' to Stream 4 for those with multiple and complex needs. While the JSCI recognises and makes allowance for the disadvantage of parents caring for children, it doesn't recognise the impact of other caring relationships (such as for a partner or elderly parent) or whether dependent children have a disability or chronic condition.
- During the 2012 inquiry into the adequacy of Newstart and the Job Services Australia program, the Senate Committee heard evidence from many in the sector that job seekers are not always accurately classified through the Job Seeker Classification Instrument and placed in the most effective job support stream. The Committee recommended that the government develop targeted and tailored programs for former carers as they move from Newstart Allowance or another payment once their caring responsibilities end.¹⁷
- 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 education and training to allow them to transition from income support to employment. Indeed over 59% of surveyed carers have been caring for between 5 and 25 years or more¹⁸.
- Carers therefore need to access more intensive and focused support to help them transition from the caring role into employment.

Recommendation 7:

- **The Job Seeker Classification Instrument (JSCI) should include specific questions that will identify carers.**
- **Jobseekers who are identified as long term carers should receive more intensive support, including a minimum of Stream 2 assistance through Job Services Australia (JSA) as soon as they enter the Job Services Australia system.**
- **All carers who are transitioning from Carer Payment to employment should have access to retraining through their job service provider and be informed of their right to retraining funding.**

¹⁷ The Senate Education, Employment and Workplace Relations References Committee, 2012, *The adequacy of the allowance payment system for job seekers and others, the appropriateness of the allowance payment system as a support into work and the impact of the changing nature of the labour market*, P.69

¹⁸ Australian Bureau of Statistics, *2009 Survey of Disability, Ageing and Carers*