This election Australian carers seek commitment in five key areas of need.

1. Continuation and growth of carer-specific supports

2. Continue investment in early intervention for children with developmental disabilities

3. Invest in the future of young carers

4. Support carer participation in education, training and employment

5. Address the disconnect between aged and disability care supports
WHO WE ARE AND WHAT WE DO

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.

We work in collaboration with carers, Carers Associations, government, the public service and related peak bodies to develop policy, undertake advocacy, manage programs and raise carer awareness to improve the lives of Australia’s 2.6 million carers.

Carers Australia works directly with the state and territory Carers Associations to deliver practical and effective programs funded by the Federal Government to support carers; such as the Carer Advisory Service, the National Carer Counselling Program, the Better Start for Children with Disability Registration and Information Service, Mental Health Carer Counselling and the Young Carers Program.

Carers Australia plays a key role in both the aged care and disability sectors, and is a member of both the National Disability and Carer Alliance and the National Aged Care Alliance. We provide input to government and relevant organisations through our representation on a number of councils, committees and working groups, and through our submissions in response to government and sector inquiries, which are based on research and consultations with carers.

Carers Australia is committed to continue working collaboratively with government and other stakeholders to guide the development of policy and programs and to promote awareness which will see Australia’s 2.6 million carers valued and supported in our community. We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socio-economic status, gender identification and geographic location should have the same rights, choices and opportunities as other Australians.

WHAT WE KNOW ABOUT CARERS

• Australia’s 2.6 million carers provide approximately 1.32 billion hours of care per year, with an estimated replacement value of $40.9 billion annually. Provision of carer supports is therefore an investment not just in carers themselves, but in the disability, health and aged care sectors, and in workforce participation.

• Carers tend to be economically disadvantaged, with 62 per cent of primary carers in the two lowest income quintiles.

• Carers have lower general wellbeing than others and are more likely to experience poor health, including an above average rating on the depression scale. Carers are also more likely to experience chronic pain or injury associated with caring.
Carers Australia is concerned with an apparently growing perception that DisabilityCare Australia (DCA) will serve the needs of all carers of people with a disability or chronic health problem under the age of 65 and that these carers will no longer need to have their own Government funded supports in place.
WHAT WE KNOW

• DCA individual support packages are for the person with a disability to achieve their aspirations, not their carer. These aspirations won’t necessarily involve replacing unpaid carer with paid care, and in many if not most cases, unpaid carers will continue to provide the support they do now – albeit with greater confidence that the person they care for will have a better lifestyle, and that some aspects of their care (for example, improved equipment and home modifications) will make things easier.

• DCA 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 DCA before they reached that age. In this context it is notable that DCA is expected to cover 460,000 people when fully rolled out. According to the 2009 ABS Survey of Disability, Ageing and Carers it was estimated that there were 680,400 people with a profound or severe core activity limitation under the age of 65.

• Under these circumstances there remains a pressing need to continue funding carer support programs outside DCA which will need to be accessed both by carers of those care recipients who do receive DCA packages (which improve their circumstances but does not remove the need for their carers) and those whose care recipients are not covered by DCA. These supports include information, referral, counselling, training, respite (especially for those carers who care for people not covered by respite available through DCA) and home help.

ELECTION COMMITMENT SOUGHT

• Funding of carer support programs will be maintained and increased in line with the growth of the unpaid carer population.
DisabilityCare Australia (DCA) will not be fully rolled out until 2018-2019 and there is concern that children living outside of areas covered by DCA will be disadvantaged unless the Better Start for Children with Disability initiative and Helping Children with Autism (HCWA) program continue to be rolled out and expanded in all areas in Australia.

All Australian children with developmental disabilities who can benefit from early interventions of the type offered under these initiatives should have the opportunity to access such services – regardless of where they live.
WHAT WE KNOW

• Early intervention lowers the costs and impacts associated with the longer term outcomes of developmental disability by alleviating the impact of a disability or preventing deterioration.

• The Better Start for Children with Disability initiative provides early intervention funding to eligible children under seven suffering from developmental delays. The Helping Children with Autism (HCWA) program provides early interventions for children in the same age group. Together these programs assist children with developmental disabilities to help improve their life outcomes.

• While DisabilityCare Australia (DCA) will eventually replace both these initiatives, the scheme will not be fully rolled out until 2018-19. During this time, it is essential that all children with a developmental disability who would benefit from early intervention, but who are unable to access DCA in their locality, continue to have access to these vital supports. Without early intervention, these children face a more difficult transition to school, find it harder to interact with their peer group and are likely to be permanently disadvantaged.

• Better Start has already provided assistance to nearly 7000 children across Australia. There was always the intention to build incrementally on the number of eligible conditions where there is a clear and proven benefit from the types of intervention available under these programs. There is certainly scope to expand the number of eligible developmental delay conditions, especially with respect to children with similar genetic conditions to those currently covered by the program and who require identical early intervention measures.

ELECTION COMMITMENTS SOUGHT

• The Better Start for Children with Disability and Helping Children with Autism initiatives (or their equivalents) will be retained until the full nationwide rollout of DisabilityCare Australia, so as not to disadvantage children outside DisabilityCare Australia sites.

• Under these programs, the number of conditions which can be allayed by early intervention will be expanded to ensure that all children who can benefit from developmental delay interventions have the same life chances.

“The Better Start Program has relieved a lot of financial burden and allowed Max to be the best he can be. I am certain that with all the help Max is currently receiving, it will directly contribute to Max being a productive member of our society as he grows.”

Mother of 4 year-old with Fragile X syndrome.
In addition to their caring role, young carers often have greater responsibilities at home, which can affect their participation and performance at school. However, many young carers are reluctant to ask for help, and may not even realise they are a carer, or may not want to identify as one due to stigma.

Evidence shows that young carers experience low levels of participation in education and employment, and consequently face reduced life choices and limited future opportunities. Targeted outreach and education support will assist young carers to have equal life opportunities to other Australians.
WHAT WE KNOW

- It is estimated that 360,000 Australians between the ages of 15 and 25 are carers – although there are also many young carers under the age of 15, including those still in primary school.

- Many of these are the primary or sole support for those they care for and other family members – often for many years.

- Young carers aged 19-24 years are less likely to have completed year 12 (or an equivalent) compared with non-carers of the same age.

- 70.6 per cent of young carers who have received Carer Allowance or Carer Payment remain on income support after completing their caring role.

- The Federal Government (with assistance from the Carers Associations) has provided booklets targeted at primary and high school to help teachers recognise young carers and the disadvantages they face educationally. However, Carers Australia’s experience is that promotion of young carer awareness is more effective if reinforced through personal contact by young carer advocates.

- Other institutions which come into contact with young carers and can point them to special support services include hospitals, tertiary education institutions, police (particularly if they are caring for someone with a mental health or substance abuse problem) and services associated with Medicare Locals.

ELECTION COMMITMENTS SOUGHT

- Funding will be provided for additional targeted outreach activities to assist hospitals, police, universities and health professionals to identify young carers and point them to available supports.

- Additional funding will be made available for specialist young carer counsellors.

- An Educational Assistance Scheme, similar to that provided to the children of defence force personnel, will be established to provide tutoring assistance for young carers in primary and secondary schools who are identified as needing additional support. In addition, further subsidisation of the administrative and resource costs associated with the establishment and extension of young carer homework clubs provided by community services organisations will be provided.

“Mum has a few different illnesses but she doesn’t speak English very well. I do a lot of the cooking and cleaning and looking after my brothers so it can be hard to find time for school work.”

Lala, young carer, age 10
Support Carer Participation in Education, Training and Employment

**The Issue**

Those who are unpaid carers for a substantial period of time are often left with little relevant employment experience or education and training to allow them to transition into the workforce when their caring role ceases. This is partly a by-product of the rules surrounding eligibility for the Carer Payment, which considerably restrict their ability to participate in education, training and employment without losing their entitlement.

There are no targeted Federal Government programs in place to support people who are transitioning from a caring role to employment.
WHAT WE KNOW

- Over 59 per cent of carers who provide more than 40 hours of care per week have been in this role for 5 to 25 years.
- It is estimated that there are some 78,000 carers who receive an income support payment (including about 18,000 on Newstart). The single rate of Newstart is now less than 45 per cent of the minimum wage and $130 per week below the poverty line.
- There are inconsistencies in the guidelines and rules operating under the Social Security Act as to what constitutes an appropriate amount and timeframe of dedicated care as pre-condition for carer income support. The rule applied by Centrelink which is known as the ‘25 hour rule’ is most restrictive of carers’ opportunities to participate in any employment, education or volunteer work while on income support. While this rule is intended to simply trigger a review of entitlement to payments, carers report it is used to trigger immediate cessation of eligibility.

ELECTION COMMITMENTS SOUGHT

- Carer-specific employment training and support arrangements will be introduced for former carers. These arrangements will apply when the person they care for has died or where their situation deteriorates to the point where they can no longer be supported at home. These arrangements will include:
  - Appropriate counselling to assist the carer to deal with grief and adjustment issues in preparation for re-entering the workforce.
  - Newstart participation requirements (such as fortnightly reporting or interviews with Job Services Australia providers) to be graduated over 6 months to allow for readjustment (including the impact of the grieving period) and to take into account those with ongoing caring responsibilities when the person they care for has moved into residential care.
  - Access to appropriate education and training, and other measures, to support carers capable of re-entering the workforce to develop or refresh appropriate skills and experience.
- There will be a review of ambiguous and inflexible Social Security Act rules which have the effect of constraining the capacity of Carer Payment recipients to participate in education and training while they are in a caring role.
- The Newstart Allowance will be increased by $50 per week.

“My income dropped about 60 per cent in that grieving period. It was very difficult and I did not know what to do.”

Mr Terry Stroud, carer for over 17 years
The Living Longer, Living Better aged care program reforms and additional funding for aged care supports promise to deliver significant new benefits for people over the age of 65. However, Carers Australia is concerned about some aspects of these reforms.
Our concerns include the following:

• Rationed aged care supports will mean not all people assessed as eligible (including carers) are able to access them.

• It seems likely that people with a disability over the age of 65 will not have access to the same level of support as their younger counterparts who are eligible for DisabilityCare Australia assistance.

• Under the Living Longer, Living Better reforms new Carer Support Centres will be established under the auspices and funding of the Health and Ageing portfolio and these will replace existing Carer Respite and Carelink Centres (CRCs). It is important for reasons of economies of scale and scope and for the integration of supports for sandwich carers (those caring for people both under and over the age of 65 at the same time) that the 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, there has been adequate opportunity for proper public consultation, and the sector has time to adjust to the new program structure.

WHAT WE KNOW

• Funding for the provision of aged care services are allocated to the providers of such services on a rationed basis per head of population, perpetuating access inequities across locations.

• It is not clear that people who acquire a disability over the age of 65 (for example, deafness or macular degeneration) will be eligible for the same supports as their younger DCA eligible equivalents.

• Carer Support Centres work best and achieve economies of scale and scope when they cater for all carers (including those caring for people with a disability, mental health problems and chronic illness) regardless of their age.

ELECTION COMMITMENTS SOUGHT

• The introduction of an entitlement-based aged care service system which delivers supports where and when they are required.

• People who acquire a disability over the age of 65 will be eligible for the same level of support that is offered to their younger DCA equivalent.

• New Carer Support Centres will be funded to provide services and supports to all carers regardless of the age and the nature of impairment of the people they are caring for.

“Aged care is rationed. Only 116 of every 1000 people over the age of 70 get the support and services they need. If you are number 117 you miss out.”

National Aged Care Alliance’s Age Well Campaign.

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