



COMMIT TO CARERS

STATE PRE-BUDGET SUBMISSION 2017 - 2018

NOVEMBER 2016

CARERS SA IS THE RECOGNISED 'VOICE OF CARERS'
REPRESENTING THE INTERESTS AND NEEDS OF FAMILY CARERS
IN SOUTH AUSTRALIA

Carers SA's submissions and responses are developed through documented research, surveys and consultation with carers and members, Carers SA working groups and focus groups of carers and service providers.

Contact:

Rosemary Warmington AM, CEO

Telephone: (08) 8291 5600

Email: info@carers-sa.asn.au

Website: www.carers-sa.asn.au

Facts and Figures

- 1 in 8 Australians have an unpaid caring role. In South Australia, there are an estimated 219,000 carers (about one in eight South Australians), with an estimated 25,700 young carers under the age of 25. South Australian primary carers provide at least 20 hours of care each week with many providing 40 hours or more.
- According to the Australian Bureau of Statistics - Survey of Disability, Ageing and Carers (SDAC) 2015ⁱ:
 - Over one-third of primary carers (37.8%) are living with disability themselves.
 - Females made up the majority of carers, representing 68.1% of primary carers and 55.5% of all carers.
 - 59,100 carers in Australia are aged under 15 years.
 - For people aged 15 to 64 years, the labour force participation rate for primary carers (57.2%) and other carers (77.2%) is lower than for non-carers (80.3%).
- Carers have the lowest collective wellbeing of any population group.ⁱⁱ
- The median gross personal income per week for a primary carer in 2012 was \$400, compared to \$600 for a non-carerⁱⁱⁱ.
- Australia is ageing^{iv} and older carers may be wearied by age as longevity for both carer and the care recipient increases. Better health for a consumer, may not necessarily be mirrored by better health for the carer as they both age.
- Carer support is not specifically covered by the NDIS which is for individual support packages for the person with a disability; and NDIS will also not cover everyone with a disability meaning they will rely on informal care.
- There are about two or three young carers in every South Australian classroom^v.

Carers SA Carer Survey 2015 “Our Carers – Our World” facts^{vi}:

- 64% of respondents have difficulty managing the needs of caring and living within their current budget.
- Increasing numbers of carers are having difficulty paying for rising energy and water bills.
- 30% of carers occasionally, or regularly go without meals.
- 1 in 5 respondents were dissatisfied with their standard of living.
- 67% never, or only occasionally, are able to afford a night away from their caring role.
- 30 % reporting their health as worse than the previous year.

Young Carers

The Carers SA’s 2016 Young Carers in SA Assessment Project – “Young Carers – What Next?” facts^{vii}:

- Average age of young carers assessed: 14.64 years old (7-23 year olds)
- 1 in 5 feel that life does not seem worth living
- 29% reported that they provide care for a family member with one or more mental health issue(s)
- 59% have to do caring tasks that upsets them
- 38% think they don’t matter
- 81% often feel stressed, 52% feel very lonely
- 40% feel so sad they can hardly stand it

Introduction

For over 25 years, Carers SA has an ongoing commitment to providing a state-wide voice for family carers in South Australia, bringing their issues and challenges to decision makers.

Anyone at anytime can be a carer. Family carers provide unpaid care and support to family and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. Carers are an integral part of the Australian health system and are the foundation of aged, disability, palliative and community care systems.

In 2015, it was estimated that there are 2.7 million carers Australia wide, with approximately 29% of these identifying as primary carers^{viii}. In South Australia, the Australian Bureau of Statistics estimates that there are 219,000 carers who provide ongoing assistance to a person with a disability or an age related frailty^{ix}. Australian youth are not excluded from caring and it is estimated that in every class room there are two or three students who are classified as young carers, with a caring role and responsibilities.

Family carers often take on or continue caring roles to the detriment of carers' wellbeing. Especially, when a need for formal assistance cannot be met. In 2012 there were an estimated 774,000 people with a disability in Australia whose need for assistance for at least one activity of everyday living could not be met by formal services^x. Primary carers and those who provide the most substantial amount of care, are also more likely to have a disability or chronic illness themselves when compared to the general population^{xi}.

Higher rates of unmet need were found amongst persons with intellectual (61.4%) and psychological (59.4%) disabilities, and 80% of carers provide cognitive and emotional support^{xii}. It is hoped, the continued rollout of the NDIS will address some of the unmet needs over the next few years. Carers' contribution in covering unmet needs, not met by formal services, needs to be acknowledged and respected.

The 2015 Deloitte Access Economics Report, 'The Economic Value of Informal Care in Australia 2015' estimates replacement value for the care provided by Australia's unpaid carers to be \$60.3 billion per year. Based on this report, Carers SA estimates the value of family carers in South Australia to be the equivalent of \$4.8 billion per annum (8% of the population).

Caring comes at a high financial cost to family carers (including retirement security). Evidence shows that caring responsibilities negatively impact on carers' time, money, housing and aspirations in life. The income of primary carers is 42% lower than the income of a non-carer. Special support to access opportunities for education, training and employment while maintaining their caring role, or after the conclusion of a caring role is important for carers who wish to increase financial independence. Such support will further strengthen the betterment of South Australia's economic outlook^{xiii}.

In South Australia specifically, the pressure of increases in costs for basic necessities like housing, utilities, food, health and transport are a particular problem for low income households^{xiv}. This results in lowered potential to generate income because of caring responsibilities, accentuating financial pressures for those who are caring. The struggles to pay for basic necessities, health and care essentials and nutrition are a balancing acts for carers^{xv}. Additional cost associated with education, obtaining additional skills and the ongoing cost of maintaining Internet access are often considered non-affordable; increasing the digital exclusion of carers in a new economy.

Initiatives to support South Australian family carers remain an ongoing imperative for the State Government to address, despite significant shifts of ageing, disability and health resourcing to the Commonwealth Government.

Our community has expectations that ‘being cared for’ is ‘a right’. This right to support^{xvi} is underpinned by the acceptance of caring as a shared responsibility of families, communities and Governments. This responsibility includes securing the health and wellbeing of carers.

This pre-budget submission reflects concerns that carers have ‘voiced’ about the impact of service reforms which significantly shift the landscape of caring, such as the roll out of the National Disability Insurance Scheme (NDIS) and changes to Aged Care, and include:

- Young carers (aged under 25 years), their wellbeing and their capacity to reach their potential as young South Australians
- Local support services for carers
- The digital divide and access to information and services in the modern economy
- Financial hardship
- Carers and employment
- Inclusive service practice around caring families
- **Upholding:**
 - all carers (as defined by the *Carers Recognition Act 2005 (SA)*)^{xvii} and their ongoing role as valued and fundamental contributors to the health system and the aged, disability, palliative and community care systems,
- Acknowledgement of the irreplaceable value of care provided by carers to the health, disability and community care sectors valued at \$60.3 billion per year and as co-contributors to the Government bottom line.

SA Carer Recognition Act 2005

The *Carers Recognition Act 2005 (SA)* enshrines recognition and support for carers and their vital role in the South Australian community. This Act, established the Carers Charter outlining seven (7) underpinning principles and an acknowledgment of the vital role of carers in the Australian community. Specifically, Principle 7 of the Carers Charter requires that: ‘*Resources are available to provide timely, appropriate and adequate assistance to carers.*’

Carers SA produced *Commit to Carers* in 2014 identifying fourteen (14) key policies and programs to support family carers in South Australia, which was subsequently endorsed ensuring commitment by the SA Labour Government to fulfil ‘*Commit to Carers*’ during their parliamentary term.

In 2014, the Government of South Australia reviewed the *Carers Recognition Act 2005 (SA)* and from the recommendations established in the ‘*We Care-Our Plan for South Australian Carers*’ (*We Care Plan*)^{xviii}. The *We Care Plan*, identifies that carers needs and issues are implicit in a number of targets in the South Australian Strategic Plan (SASP) in the following areas:

- Improving Wellbeing
- Building Communities
- Expanding opportunity (p.6)^{xix}

In preparation for the State Pre-Budget Submission 2016-2017, Carers SA submits the following key seven (7) items from Carers SA’s *Commit to Carers*, which have been updated to reflect the current environment, so that South Australia can appropriately support all South Australian carers.

Budget Commitments Sought: 2017-2018

These 8 (eight) budget priorities have been identified by Carers SA for their: cost neutral impact; positive return on government investment in family carers; the positive outcomes for the carer population and caring

families; benefits to the general South Australian community who need care in their homes because of illness, disability or frailty.

Carers SA calls on the State Government to commit to the following:

- 1. Maintain and extend ongoing current (funded until 30th June 2017) State Government (identified as HACC funded) funding for local and regional dedicated specialised Carer Support programs in SA supporting carers of people with disability under 65 years for up to 5 years and increase annually by a minimum of the CPI. Without funding, these programs will be lost as will be the support for thousands of South Australian carers.**

We Care Plan Priority 2 (Outcome 4) states: 'Services provided to the public are accessible locally and able to adapt to the needs of local communities', through Government and Government-funded services addressing the social, emotional and physical needs of carers, whatever their caring situation.

- 2. Continue to provide ongoing resources to Carers SA beyond 30th June 2017 to fulfil its state-wide sector development role to promote and provide advice on best practice in relation to carers and the development and dissemination of information resources on relevant topics to fulfil requirements of the We Care Plan.**

We Care Plan commits the Government to implementing, supporting and monitoring the implementation of the Plan, both within Government and Government funded organisations and in doing so promote and provide advice on best practice in relation to carers and develop and disseminate information resources on relevant topics.

We Care Plan commits the Government and Government funded organisations to consult with carers or persons or bodies that represent carers in policy or program development and strategic or operational matters.

- 3. Provide ongoing support to include considerations of carers in South Australia's Active Ageing strategies.**

Ensure that Active Ageing strategies include specific opportunities for SA's ageing carers who continue their caring role. Better health and active ageing for a person receiving care may not necessarily be mirrored by better health and active ageing opportunities for the carer as they both age.

The 'Prosperity Through Longevity – SA's Ageing Plan 2014-2019'^{xx} aims to ensure that: 'South Australians have a fulfilling, active and enjoyable life at every age, gaining the maximum benefit from longevity linking personal wellbeing with social and economic productivity by developing dynamic and innovative state government policies and programs to enable increased participation and wellbeing of older people.'

We Care Plan Priority 2 (Outcome 4) states: 'Services provided to the public are accessible locally and able to adapt to the needs of local communities'.

- 4. Maintain the spirit and impact of the *Carers Recognition Act 2005 (SA)* by:**

- a. Reviewing outcomes and actions against the SA Government's We Care Plan 2014.
- b. Providing annual reports to Parliament on the Government's effectiveness in meeting its obligation under the *Carer Recognition Act 2005 (SA)* and We Care Plan.
- c. Ensuring that carers are represented on emerging, current and ongoing advisory structures where Government planning and strategies cover topics and jurisdictions that impact on the role of carers, or the person they care for who might be the consumer, client or patient.

- d. Promote carers' contribution across the health and disability sectors.
- e. Promote and support annual National Carers Week in SA and other relevant events related to carers and seize opportunities to promote the contributions of their caring role.

5. Develop and promote employee carer policies and procedures, by further building on existing initiatives to develop and promote employee carer policies and procedures to all SA businesses and employers, through providing tax incentives for businesses to innovate and/or implement employment conditions that support employees with additional caring responsibilities.

Research demonstrates that businesses will continue losing money, and risk losing valuable, experienced employees if action is not pursued^{xxi} to enable people with caring responsibilities to gain and remain in work. Business losses will translate into further revenue loss for government.

6. Increase public awareness and increase campaigns to support the need for family carer friendly schools, tertiary education settings and work places, as a vital component to balancing and sustaining family carers throughout their education and workforce participation.

We Care Plan Priority 1 (Outcome 3) states: 'Flexible work arrangements and leave provisions are assisting employees with caring responsibilities to balance working and caring.'

We Care Plan Priority 1 (Outcome 4) states: 'Employees and managers are informed about carer-friendly policies and entitlements and about external assistance available to carers.'

We Care Plan Priority 5 (Outcome 3) states: 'Young carers are supported during times of transition, for example, when moving from school to further education or work'.

7. Develop a State Government funded carer wellbeing and other related initiative to support young carers (under 25 year old) in their caring role as well as the wellbeing and resilience^{xxii} of young carers; to either make the transition to a full time caring, or a transition to combining employment or (tertiary) education with their caring role.

We Care Plan Priority 5 (Outcome 3) states: 'young carers are supported during times of transition, for example, when moving from school to further education or work'. Supporting young carers in our community is vital. Younger carers require life options and support in continuing their caring role beyond their youth.^{xxiii}

8. Support local, state and federal initiatives that ensure equal and stable access to online services and digital literacy, information and supports for carers and their families. In particular, those in rural and remote regions to combat distance and geographical isolation. Also, including skills development and training for carers to overcome the digital divide.

We Care Plan Priority 3 (Outcome 3) states: 'Carers have the information and resources necessary to make choices about care they provide and the supports they receive'. The increasing provision of information and service access (by Governments and funded organisations) via digital means is creating a digital divide and poor social inclusion for carers who do not have the knowledge or devices, or the financial means; this ultimately impacts their capacity to continue care as well as their health and wellbeing.

-
- ⁱ Australian Bureau of Statistics (2015) *Disability, Ageing and Carers, Australia: Carer*
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>
- ⁱⁱ Carers Australia, Submission to National Commission of Audit, citing the Australian Wellbeing Index Survey, Deakin University, 2007
- ⁱⁱⁱ Carers Australia, Submission to the National Commission of Audit
- ^{iv} An Ageing Australia, Productivity Commission, November 2013
- ^v Carers Australia derived from the Survey on Disability, Ageing and Carers, ABS 2012
- ^{vi} Carers SA Carer Survey 2015 “Our Carers – Our World” survey: Summary Results <http://tinyurl.com/o23v2tu>
- ^{vii} Carers SA’s 2016 Young Carers Assessment Project – “Young Carers – What Next?”: <http://carers-sa.asn.au/Assets/Files/Carers%20SA%20Young%20Carers%20-%20Sector%20Forum%20Paper%20Research%20Oct%202016.pdf>
- ^{viii} Australian Bureau of Statistics - Disability, Ageing and Carers, Australia: Summary of Findings, 2015
<http://www.abs.gov.au/ausstats%5Cabs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument>
- ^{ix} Government of South Australia <http://www.sa.gov.au/topics/community-support/carers>
- ^x Australian Bureau of Statistics (2012) - *Unmet Need for Formal Assistance*
<http://www.abs.gov.au/ausstats%5Cabs@.nsf/0/1FE57ED300CC4F76CA257EC00012BB44>
- ^{xi} Carers Australia Media Release Oct 2016 <http://www.carersaustralia.com.au/storage/20161018-abs-sdac-2015.pdf>
- ^{xii} Australian Bureau of Statistics - Disability, Ageing and Carers, Australia: Summary of Findings, 2015
<http://www.abs.gov.au/ausstats%5Cabs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument>
- ^{xiii} Government of South Australia, Budget Overview 2016-17
http://servicesa.cdn.on.net/budget201617/pdfs/budget/2016-17_budget_overview.pdf
- ^{xiv} South Australian Council of Social Services (SACOSS), 69th Annual Report 2015-16 <http://bit.ly/2f6Dlz7>
- ^{xv} Carers SA Carer Survey 2015 “Our Carers – Our World” survey: Summary Results <http://tinyurl.com/o23v2tu>
- ^{xvi} Clements, L 2013 Does Your Carer Take Sugar ,Carers NSW
- ^{xvii} Available at: <https://www.legislation.sa.gov.au/LZ/C/A/CARERS%20RECOGNITION%20ACT%202005/CURRENT/2005.55.UN.PDF>
- ^{xviii} Available at: https://www.dcsi.sa.gov.au/_data/assets/pdf_file/0004/23566/We-Care-Our-Plan-for-SA-Carers.pdf
- ^{xix} Ibid
- ^{xx} SA Health - Office for the Ageing, 2014, ‘Prosperity Through Longevity: SA’s Ageing Plan Our Vision 2014-2019’
 available at: <http://bit.ly/2eYQOKY>
- ^{xxi} Department of Health, UK, 2013, ‘The Supporting Working Carers Report’, available at: <http://tinyurl.com/leqeelq>
- ^{xxii} PERMA Model: Seligman, M. 2013, ‘Building a State of Wellbeing – A Strategy for South Australia’, available at:
http://ccin.qn.apc.org/images/7/7a/9f99425e3a_reduced.pdf and
 Seligman, M. E., Ernst, R. M., Gillham, J., Reivich, K. & Linkins, M. 2009, ‘Positive education: Positive psychology and classroom interventions’, Oxford Review of Education, 35:3, pp. 293-311.
- ^{xxiii} Carers Australia ‘Combining Work and Care: The benefits to carers and the economy’ available at:
<http://www.carersaustralia.com.au/storage/Work%20&%20Care%20Benefits.pdf>