

## Carers ACT

### 2020 Budget Submission

# The next step towards a Canberra that Cares for Carers

A proposal for the continued funding of the ACT Carers Strategy to enable Carers ACT to continue to lead the implementation of the 25 actions in the 2018-2021 Action Plan. Investing in supporting more than 48,000 unpaid carers in the ACT is an investment in the future of the ACT. Investing in the wellbeing of Canberra's carers will ensure that they are capable and willing to continue to provide the assistance with daily living for Canberra's living with disability, chronic or mental health conditions, are frail aged, require palliative care or are caring for children in the Care and Protection System. Investing is delivering on the Government's commitment to carers.

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## Executive Summary

In 2018 the ACT Government endorsed the first three-year action plan for the ACT Carers Strategy. \$250,000 was committed in the 2016 election for the development of the Strategy. These funds will be fully expended by June 2020 and there is currently no funding committed to the on-going implementation of the Strategy. The ACT Carers Strategy Action Plan 2018 – 2021 outlines 25 actions towards meeting the Strategy goals and outcomes.

There are more than 48,000 family and friend carers in the ACT. Reaching the outcomes and vision of the Carer Strategy will have a significantly positive impact on all of Canberra's carers.

Carers ACT has worked collaboratively with the ACT Government over the past three years to lead the formation of the ACT Carer Strategy. Further funding is required if Carers ACT is to play the vital role that it needs to play to support the ACT Government to achieve its vision of 'a community that cares for carers and the people they care for'. Carers ACT is calling for funding of \$950,000 per annum over four years to implement the strategies of the first three year action plan of the ACT Carer Strategy, work with the Government to form the second action plan for 2021-2024 and increase service delivery and supports for carers within the ACT.

Outcomes to be achieved from the funding include:

- 1) Delivering on the government's commitment to carers through the Carers Strategy;
- 2) Improvement in the overall wellbeing of carers;
- 3) Increased capacity to continue in the caring role and thus reduced hospital presentations and replacement care costs;
- 4) Increased services and supports for carers;
- 5) Carers report feeling more valued and acknowledged in their caring role; and
- 6) The views of carers are considered in the planning and delivery of services that enhance the health, wellbeing and inclusion of them and the people they care for.

## Section One: Objectives and Needs Analysis

### Key Problem

In 2017/18 the ACT Government, carers and the community sector worked together to develop the ACT Carers Strategy 2018-2028 as a response to working collaboratively towards improving carer outcomes. The initial three-year Action Plan identifies five themes which provide the foundation for delivering services for carers in the ACT.

In 2016 the ACT Government committed \$250,000 for the development and implementation of the Carer Strategy. This money will be fully expended by June 2020 and there is currently no allocation of funding for the implementation of the actions in the Action Plan or for the development of the second Action Plan.

The need for a Carer Strategy is underpinned by the 2007 Australian Unity Wellbeing Index survey undertaken into collective wellbeing of carers found that carers scored lower outcomes of any group investigated and that carers who live with the person requiring care had the lowest wellbeing ever recorded (Australian Unity Wellbeing Index Survey, 2007). They proposed that the key factors in maintaining personal wellbeing for carers are strong relationships, financial control and a sense of purpose.

Carers ACT applauds the government's commitment to carers through the endorsement of the 10-year ACT Carers Strategy. We call on the government to continue this commitment through allocation of funding to implement the actions required to improve the wellbeing of carers and through this the wellbeing of the people they care for.

Carers ACT is the lead in 20 of the 25 actions and support agency for 4 of the remaining 5. We ask the government to commit \$950,000 per annum for 4 years to enable Carers ACT to continue to work in partnership with carers, government and community to step towards improving the wellbeing of a vulnerable group within the ACT Community.

### Evidence

Research both within Australia and Internationally provides compelling evidence about the impact of caring on personal wellbeing (Hill and Broady, 2019) often highlighting that the time and resources required for caring can affect a carer's social wellbeing (ABS 2015; Productivity Commission, 2011). The General Social Survey (ABS 2014) found that people with caring responsibilities were more likely to experience social isolation and thus more vulnerable to developing mental health conditions. The time taken for caring reduces the carer's ability to participate in their community and interact with their family and friends. Whilst there is strong evidence of the therapeutic impacts of time away from the caring role, there are also benefits to the carer, person with a disability and the family of increased participation and involvement in community life. Addressing the lower levels of participation

of people with a disability and their carers will lead to improve outcomes particularly in the areas of health and life satisfaction (Productivity Commission, 2011).

An analysis of the research demonstrates the key areas of impact for carers include:

## Physical health

- it is recognised that Carers are less likely to attend medical appointments for themselves, to delay treatment (especially if the treatment impacts on their ability to care for their loved one) and to prioritise the health needs of the care recipient over their own.
- sleep deprivation and accompanied fatigue impact on physical and emotional health. Lack of quality sleep impacts on a person functioning. For carers the ability to access regular uninterrupted sleep can have devastating long term effects on their ability to maintain their caring role.
- According to a longitudinal study on Australian Women's Health (Tooth et al., 2018) live-in carers are more likely to –
  - have poorer self-reported health,
  - be less physically active,
  - to smoke,
  - to be obese,
  - have poor adherence to recommended fruit intake,
  - ignore pap test recommendations,
  - have increased levels of stress, anxiety and depression,
  - make more visits to the GP and an increased number of scripts filled and,
  - be 3x more likely to have chronic conditions (specifically breast, cancer, diabetes, asthma, heart disease, stroke, and arthritis).
- The longitudinal study found that the impacts on health of women experiencing family violence and women in caring roles were comparable, with both groups being more likely to have higher stress, more depressive symptoms, and poorer physical health than non-carers and people not experiencing family violence. The study indicated that health measures increased with better personal resources like resilience and social support.

## Mental Health

- the burden of care often impacts negatively on the mental health of the carer. A key part of maintaining personal wellbeing is the ability to respond and recover from adversity over time. For many carers the experience of chronic stress and burden from caring impacts on their psychological wellbeing and can lead to mental illness such as anxiety and depression.
- Tooth et (2018) found that carers who report feeling satisfied and supported in their caring role were 50% less likely to have thoughts about life not being worth living than those that were dissatisfied. Those dissatisfied also reported poorer physical and mental health, higher anxiety levels, lower optimism, and less social support.

- female carers who have depressive symptoms who do not gain satisfaction from the caring role or feel a lack of support would be likely risks for suicide (O'Dwyer, Moyle, Pachana, Snug and Barrett, 2014).
- "caring itself is associated with increased risk of CMD (common mental disorders) that is not explained by other identified social stressors....Carers are also more likely to experience stressors other than caring and it is likely that they will need support not only aimed at their caring role, but also at other aspects of their lives" (Stansfeld et al., 2014, p190).

## Financial burden

- the caring role often comes with significant costs such as medical expenses, specialised equipment and household expenses above the average for the rest of the population. Whilst there are supports in this area to alleviate some of the financial cost it is recognised that the carer group has a larger financial burden compared with the average person.
- it is important to acknowledge the long-term cost of unemployment for carers. Carers are less likely to have access to superannuation income in their retirement.

## Isolation

- caring responsibilities lead to isolation. The demands of caring are constant, and the effort required to access appropriate substitute care for the person they care for often results in carers avoiding leaving the house and engaging in social activities.
- Changes in the health of the person cared for often impacts on the amount of informal care required and can result in reluctance to commit to planned activities.
- Carers often sacrifice their own need for social inclusion to ensure the needs of the cared for person are met. Caring demands can mean carers are unable to plan ahead, they are time poor, have ill health, and financial stress. Carers identify that clear information, high quality care and respite, and flexible workplaces are essential to reducing their social inclusion (Hill et al, 2016).

## Relationship

- the relationship between carer and care recipient is often complex and there is a level of interdependence. This often involves feelings of frustration, guilt and regret as well as feelings of love, companionship and support.
- Carers experience grief and loss watching the care recipient's changes in health condition, declining function and experience of acute or chronic pain.
- Carers also experience grief and loss of former relationship, changes in role and future hopes and dreams.
- The concept of personhood - a degree of separation from and less enmeshment with person cared for - has been identified as an important factor in maintaining carer wellbeing. Carers often feel guilty about aspects of their relationship with the person they care for and any desire for a degree of separation from the person they care for.

## Use of Time

- Caring long term for someone often means that the carer forgoes opportunities to fulfil other activities or opportunities in life. Over time this can impact negatively on the carers sense of self and identity, often leading to feelings of regret, frustration and a loss of self-esteem. It can also impact on the carers desire to maintain the caring role.
- According to the Survey of Disability, Aged and Carers (ABS 2015) 20.9% of carers (1,900 people in the ACT) live in the same household as a person aged 15 to 64 years of age with a profound disability requiring more than 40 hours of care per week and 37.9% (800) are providing more than 40 hours per week care to someone over the age of 65 years in their household.

## Why Now?

In the 2016 election campaign the Labor Party agreed to the formation of an ACT Carer Strategy and committed \$250,000 (including in-kind support from the Community Services Directorate) for its development.

The commitment to the development of an ACT Carers Strategy was cemented in the Parliamentary Agreement for the 9<sup>th</sup> Legislative Assembly for the Australian Capital Territory. This document stated that “ACT Labor and the ACT Greens understand that government has an active and positive role to play in making sure everyone in our community is supported, welcomed and has the opportunity to reach their full potential. The parties therefore agree to: develop a carers strategy in close consultation with Carers ACT, disability groups and other affected community members”.

In August 2017 a panel of 48 carers from the ACT was formed to undertake a deliberative democracy process to form the ACT Carers Strategy. This Strategy reflected the combined views of carers from across all parts of the community. In December 2017 the ACT Government endorsed the Carers Strategy for a 10-year period from 2018 -2020.

In February 2018 a taskforce comprising of carers and representatives of government and community agencies was formed to develop the first three-year action plan for the achievement of the outcomes of the ACT Carers Strategy. In October 2018 the ACT Government endorsed the first three-year Action Plan.

In April 2019 the Community Services Directorate entered a funding agreement with Carers ACT to allocate the remaining \$50,000 (from the initial investment of \$250,000) towards the achievement of the Action Plan. This was in recognition that Carers ACT is the lead agency for 20 of the 25 actions in the Plan and is the support agency in 4 of the remaining 5. Expenditure of this funding will be complete in early 2020. Without additional funding being allocated in the 20/21 Budget we will not be able to continue progress towards achieving the goals of the Action Plan and ultimately the outcomes of the ACT Carers Strategy.

## Section Two: Details of the Proposal

A summary of the key themes and actions in the ACT Carer Strategy Action Plan are as follows:

Theme	Action
Services and supports	We support carers to find and use services to care for their health and wellbeing.
Recognition and awareness	We recognise the important contribution carers make to the community.
Young carers	We support young carers to finish school and achieve their goals.  Young carers are resilient and connected to their community.
Inclusion	We include carers in decisions that impact them.  We recognise carers' expertise about the people they care for.
Workforce and skills recognition	We recognise carers' knowledge and skills in workplaces.  We support carers to balance work with their caring role.

Carers ACT is the leading body for Carers in the ACT. We work to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We also work to ensure that caring is acknowledged and recognised as a shared responsibility of family, community and government.

Our purpose is to support, connect and empower carers to maintain their caring role and personal wellbeing.

Carers ACT is identified as the lead agency in 20 of the 25 actions and supporting agency in 4 of the remaining 5. Carers ACT has worked in partnership with carers and the government since 2016 to deliver the ACT Carers Strategy and we are seeking to continue this collaboration. We are requesting a budget allocation of \$950,000 per year for four years to deliver the following outputs:

- 1) Lead and support the implementation of the 25 actions in the ACT Carers Strategy Action Plan
- 2) Facilitation of a yearly deliberative panel with carers to provide feedback on progress against the achievement of the Carer Strategy
- 3) Provision of policy advice across government on carer issues and the impact of policy decisions on carers

- 4) Provision of carer input and engagement in Canberra Health Services, Health Directorate, Community Services Directorate and Education Directorate to ensure the implementation of policies and practices that are carer inclusive and improve the wellbeing of carers
- 5) Specialised assistance and provision of individualised supports, including respite, to at least 50 carers per year providing more than 20 hours care, particularly to people with complex chronic health conditions, to enable them to engage in activities that lower their stress and increase their wellbeing
- 6) Piloting of a carer mentoring program that enables carers with experience to provide support, assistance and information to new and young carers
- 7) Developing programs that empower, education and enable carers and through this reduce reliance on the hospital system
- 8) Deliver carer awareness and recognition activities
- 9) Pilot new services and supports that enable carers to maintain or increase their wellbeing
- 10) Development of the second three-year Action Plan for the achievement of the ACT Carers Strategy

### Revenue required and proposed expenditure

Carers ACT requires an investment of \$950,000 per year for four years to deliver the outputs and outcomes described above. This revenue would be used to fund:

Item	Function	Cost
1 FTE Level 7 staff member	Lead formation of project plans to ensure achievement of the Action Plan Work collaboratively with Directorates to implement systemic changes in policy, legislation and service delivery Provide oversight and monitoring of the implementation of the Strategy Actions Development of the second Action Plan with high level of carer engagement and input	\$130,000
2 FTE Level 6 staff member	Development and implementation of new programs such as the mentoring program, co-ordination of the provision of carer engagement and programs that build capability and capacity in carers who are high users of the health system	\$220,000
1 FTE Level 4 staff member	Specialised assessment of need, assistance and provision of individualised supports, including	\$90,000

	respite, to at least 50 carers per year providing more than 20 hours care, particularly to people with complex chronic health conditions, to enable them to engage in activities that lower their stress and increase their wellbeing	
Purchase of specific supports, including respite supports, for high stress and high load carers	<p>Provision of supports that build resilience, support the ongoing carer role, improve wellbeing and enable better health outcomes for high risk and vulnerable carers.</p> <p>Provision of respite supports for carers not eligible through federal government initiatives</p>	\$150,000
Program activities to support the implementation of the Carer Strategy Actions	<p>Purchase of resources, programs and activities to support the increase of services available to support carers in the ACT</p> <p>Reimbursements for volunteer expenses and carer participation/contributions</p>	\$60,000
Yearly deliberative panel for provide feedback on progress and direction for the coming year	<p>Ensure continued engagement with carers</p> <p>Provide feedback to carers on progress</p> <p>Obtain engagement in the activities proposed for the following year</p> <p>Maintenance of the Strategy being driven by carers</p>	\$50,000
Continue partnership with Democracy Co to undertake deliberative democratic processes to develop the second three-year action plan	<p>Maintenance of data on the progress of actions in the first plan</p> <p>Collection of data and analysis of impact of the plan</p> <p>Engagement with carers and other stakeholders to form the basis of the second plan</p> <p>Annual facilitation of stakeholder workshops to report on progress and form the new action plan</p>	\$50,000
Corporate support	Rent, utilities, IT, training and supervision, governance and leadership, financial support, HR support, stationery and consumables, corporate support for reporting, quality improvement, contractual management	\$200,000

## Potential cost savings from an investment in carers

There is a growing body of research that is indicating that family carers play a substantial role in the frequency of unnecessary hospital presentations and extended lengths of hospital stays (see for example Worthington and Rooney (undated); Toh, Lim, Yap and Tang, 2017; Horsfall, Leonard, Rosenberg and Noonan, 2017; Li, Srasuebkul, Reppermund and Troller, 2018)

There are significant economic costs associated with unnecessary hospitalisations or re-presentations at Emergency Departments. Much research has been conducted on how the costs associated with this can be decreased. Grealish et al.'s (2017) research on re-presentation into the Emergency Department of hospitals within 28 days of discharge found common factors that presented logical solutions. The authors posited that engaging with carers, focusing on advanced care planning, using integrated care models, and better discharge summaries could potentially change re-presentation rates and thus lower the demand in Emergency Departments.

There are a number of preventative strategies that would create impactful results towards lowering the avoidable hospital admissions and re-admission rates. If carers had education about the needs of people with chronic disease and how to avoid exacerbating certain conditions and skill development on how to advocate for the person they care for so that they get the supports they need on their first presentation we may see a reduction in reducing unnecessary re-admissions or presentations.

Research indicates that the provision of information, advocacy, and follow up visits and calls improved physical and emotional wellbeing and reduced hospital readmissions. Having social supports and education are key to a successful post hospital recovery and reduced readmission (ACTCOSS, 2019).

Horsfall et al., (2017) posit that, particularly carers for people at the end of life, carer wellbeing and their ability to maintain the caring role is affected by being able to support their cared for person at home. The connections of comfort, belonging, familiarity, relationships all created a caring experience which focused on 'pleasure, achievement and a sense of purpose within the home'(p63).

Effective, timely and appropriate support for carers can help meet outcomes such as:

- Lowering the average length of hospital stay
- Decreasing hospital waitlists
- Reducing the number of unnecessary hospitalisations
- Reducing the number of emergency department presentations
- Reducing the number of emergency presentations for people requiring palliative care.

The economic benefits of supporting the implementation of the ACT Carer strategy are multiform and include:

- improved wellbeing of carers, a vulnerable group, and the associated cost savings of wellbeing
- reduced re-presentations and unnecessary emergency department presentations and associated costs due to improved self-care, education and knowledge of carers who are influential in determining hospital presentations
- reduced length of hospital stays and associated costs due to increased capacity and willingness of carers to provide care at home
- reduced health costs associated with providing health care to carers who have been negatively impacted by their caring role
- reduced costs of providing replacement care through the reduction in relinquishment resulting from carer burnout

## Section Three: Stakeholders and Consultation

The ACT Carers Strategy was formed through a deliberative panel comprising of 48 ACT carers. The panel included representatives of carers of people with disability, chronic health conditions, mental illness, who are frail aged, require palliative care or are carers for children and young people in the out of home care system. The Carers Deliberative Panel was the first use of deliberative democracy practices in the ACT. This approach ensured that the people most impacted by the strategy were engaged and directly responsible for the formation of the goals and outcomes of the Strategy.

Key stakeholders including representatives from each Government Directorate, Peak Community Agencies, Young Carer Agencies and carers were involved in the taskforce that developed the three-year Action Plan following the endorsement of the Strategy by the ACT government.

ACT Peak Bodies and Members of ACTCOSS have endorsed the funding of the ACT Carer Strategy.

## Section Four: Policy Alignment

The proposal aligns with a number of current ACT Government Initiatives including:

- ACT Carers Strategy
- ACT Disability Justice Strategy
- ACT Office for Mental Health and Wellbeing Work Plan
- ACT Health Directorate Strategic Plan
- Canberra Health Services Strategic Plan
- Regional Mental Health and Suicide Prevention Plan
- ACT's Aged Friendly City Plan
- ACT Women's Plan
- ACT Multicultural Plan
- A Step Up for Our Kids
- Territory Wide Palliative Care Plan
- ACT Preventative Health Plan

## Section Five: Outcomes

Carers ACT will work collaboratively with the ACT Government to develop an approved implementation plan and performance indicators.

The funding would achieve the following outcomes:

- 1) Delivering on the government's commitment to carers through the Carers Strategy
- 2) Improvement in the overall sense of wellbeing of carers as measured through the annual administration of the Personal Wellbeing Index
- 3) Significant reduction in stress, improvement in wellbeing and capacity to continue in the caring role for carers with high caring loads supported through individualized supports
- 4) An increase in the perception of carers that Canberra is a community that cares for carers
- 5) Carers involved in the governance of the ACT Carer Strategy report high levels of satisfaction with progress to achieving the Strategy outcomes
- 6) Carers report feeling more valued and acknowledged in their caring role as measured through the annual Carers ACT survey
- 7) The views of carers are considered in the planning and delivery of services that enhance the health, wellbeing and inclusion of them and the people they care for

## Section Six: Why Carers ACT

Carers ACT is the only carer specific service in the ACT with 25 years' experience, annually supporting more than 3,500 ACT carers. We are carer centric with a constitutional object of working to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We provide a range of DSS funded carer programs, DoH Aged Care and Carer programs and ACT funded services. We are recognised for our quality service delivery and expert local knowledge,

We know carers personally and statistically. We listen to carers and advocate for the principles in the Statement for Australia's Carers. We understand the challenges and exhaustion, appreciate the tension between love and despair and understand the emotional and physical strain. We know that carers want to be acknowledged and recognised and they want to participate socially and economically. Our diverse workforce mirrors the diversity of our carers and enables us to provide accessible services that are responsive to the needs of individuals and groups.

Carers ACT has a strong history of delivering quality outcomes under a range of government contracts. To implement the proposed activities, Carers ACT will draw on our

- established workplace culture of delivering respectful, inclusive and welcoming services to carers
- workplace performance practices that include regular discussions about values and behaviours
- commitment to collaborative practices and established relationships
- client centred practices that put carers at the heart of everything we do
- established quality improvement practices that support a culture of courage to do better
- reputation as an established, trusted, expert to ensure accessible and safe services
- expertise in service implementation and delivery
- experience in delivering outcomes in alignment with grant requirements
- knowledge to ensure culturally safe practices are adopted
- governance practices
- established policies and procedures including risk management

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