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FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING
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Submission Cover Sheet

Inquiry into Carers Recognition Bill 2021

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Carers ACT



INQUIRY INTO CARERS RECOGNITION BILL 2021

Carers ACT July 2021

ABOUT CARERS ACT

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. The Carer Recognition Act 2010 defines carers as people who provide personal care, support and assistance to people with disability, medical condition (including terminal or chronic illness), mental illness or frail age. Carers include family members, friends, relatives, siblings or neighbours.

In the ACT more than 50,000 people provide care. Carers provide an important role in the family and in the broader community, supporting the quality of life of the person they care for. A carer's role can include help with daily living activities such as housework, transport, health care, shopping and meals, reading and writing, emotional and mental support and personal care.

According to the ABS one in ten children and young people provide informal care in families with disability, mental health or chronic health conditions or to people who are frail aged or requiring palliative care. Young carers can be as young as 4 years old and can be the sole carer in the family.

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INTRODUCTION

Carers ACT welcomes and supports the introduction of the inaugural Carers Recognition Act in the ACT. As the leading body for carers in the ACT we passionately advocate for the rights of carers and for the inclusion of carers in the decisions that impact their lives.

In 2018 Carers ACT proudly supported the development and endorsement of the 2018-2028 ACT Carers Strategy and celebrated the voices of carers who called strongly for a Canberra that Cares for Carers. We have walked alongside carers for 30 years as they fought to be seen and acknowledged, to have their role valued and recognised to be supported to undertake the caring role with minimal impact on their health and wellbeing.

The introduction of the Carer Recognition Bill in the ACT Legislative Assembly in June 2021 was the culmination of the journey we started in 1991 and we cemented in 2018.

Carers ACT submits to the Standing Committee on Health and Wellbeing our Position Statement 2021 which articulates the need for a Carers Recognition Bill and our response to the draft bill provided to Ms Orr MLA in March 2021. Our Position Statement draws from the latest research into the impact and needs of family and friend carers and our submission to the draft bill reflects what we heard from carers about the bill.

RECOMMENDATIONS

Carers ACT recommends that:

- 1) The Carer Recognition Bill as referred to the Committee on Health and Wellbeing is supported
- 2) That there are no changes to the reporting requirements outlined in the Carer Recognition Bill as this requirement provides carers with assurance of change and accountability
- 3) That any changes to the Bill are verified with carers as being acceptable before being endorsed.

In implementing the Act it would be valuable to consider the following recommendations made by carers:

- 1) It is recommended that government and non-government organisations alike take steps to plan how to be more deliberative in their work with, and for, carers.
- 2) It is recommended that employers seek training to understand the legal requirements of the Act but also the intention of the Act and how they can engage with their employees who are carers to better understand the issues their employees are having rather than ignore them or assume what these needs are.
- 3) It is recommended that organisations that provide support to carers seek to understand the various forms of caring, the multiple demands that can come from this, and how they might offer specific support via connecting to carers in open discussions about what would be helpful in individual cases.
- 4) It is recommended that organisations consider how they will champion the Act based on the intent of the Act rather than the obligations of the Act.

POSITION STATEMENT – CARERS 2021

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.

Definitions:

Carer:

- The National Carer Recognition Act 2010 defines carers as people who provide personal care, support, and assistance to people with disability, medical condition (including terminal or chronic illness), mental illness or frail age.
- Carers include family members, friends, relatives, siblings, or neighbours.

Wellbeing:

- A state which exists when a person's social and emotional needs are met, and the person can cope with the normal stresses of life (Hill and Broady, 2019).

Background:

Carers provide an important role in the family and in the broader community, supporting the quality of life of the person they care for. A carer's role can include help with daily living activities such as housework, transport, health care, shopping and meals, reading and writing, emotional and mental support, and personal care.

Carers identify many positive aspects to their caring role, including the opportunity for personal growth, development of new skills, companionship, fulfilment, satisfaction of knowing you have helped someone who needs you, and the opportunity to improve the person's quality of life (Hill and Broady, 2019).

Whilst caring can be very rewarding and carers describe many positives in relation to their caring role such as companionship, fulfilment, and enjoyment and satisfaction, the informal caring role often has personal costs for the carer. Caring can be stressful — emotionally, physically, mentally, and financially. It can impact on a carer's ability to participate in everyday activities, their relationships, their health, and wellbeing. Caring can lead to social isolation and loneliness and over time it can be difficult for the carer to maintain their identity as an individual and to fulfil other valued roles in life. For some carers it can even lead to depression and anxiety.

This position statement forms the basis on which Carers ACT delivers services in support of our clients and outlines the key indicators to achieving a community where carers are supported, connected, and empowered to undertake their caring role and to maintain their personal wellbeing.

Legislative Framework:

Awareness of the role of informal carers in maintaining the quality of life for the person they care for has developed significantly over the past 10-15 years. Research into the caring role has consistently highlighted the need for recognition and support for informal carers in undertaking their caring role (CoA, 2010, FAHCSIA, 2011; DHS Victoria, 2006). Carer Strategies and Action Plans aimed at increasing awareness and recognition of the value of informal carers have been developed both within Australia and internationally. (HM Government, 2010; Ministry of Social Development NZ, 2014).

The Australian Government is committed to reforming carer services to improve carer wellbeing, increase their capacity, and support their participation socially and economically.

The National Carer Strategy (2011) identifies six priority areas for carers in Australia as part of the Australian Government's long-term commitment to better respond to the needs of carers.

- Recognition and respect
- Information and access
- Economic security
- Services for carers
- Education and training
- Health and wellbeing

The introduction of the National Carer Gateway in 2020 is contributing to this vision by:

- Raising awareness – carers and their family and friends along with the general community are aware of carers and the support and services available.
- Improving knowledge – carers are better informed about the caring role and the associated stresses.
- Developing skills – carers gain skills to manage stress associated with the caring role.
- Implementing policy – prioritise investment towards carers most in need, and low-cost, preventative, services.
- Providing support – carers are able to access crisis services.
- Enhancing economic measures - improve the effectiveness of supports and services available to carers.

At a Territory level, 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.

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	<p>We include carers in decisions that impact them.</p> <p>We recognise carers' expertise about the people they care for.</p>
Workforce and skills recognition	<p>We recognise carers' knowledge and skills in workplaces.</p> <p>We support carers to balance work with their caring role.</p>

Now that we are through the first three years we anticipate building on this foundation with further support and funding from the ACT Government and the passage of the ACT Carers Recognition Bill 2021.

Many of the indicators of wellbeing in the ACT Wellbeing Framework reflect the themes of the ACT Carers Strategy and highlight the need for targeted focus on carers. The domains of the Wellbeing Framework align to the outcomes of the ACT Carers Strategy and the principals in the ACT Carer Recognition Bill 2021. These include Access and Connectivity, Education and life-long learning (especially for young carers), Governance and Institutions, Health, Housing and Home, Identity and Belonging, Living Standards and Social Connection.

What is carer wellbeing?

Social and emotional wellbeing has been defined as “a state which exists when a person’s social and emotional needs are met, and the person can cope with the normal stresses of life” (Hill and Broady: 2019). In this definition social needs include needs related to family relationships, community acceptance and involvement in relationships. Emotional needs include needs for a sense of comfort, belonging, understanding and reassurance in times of stress and upset.

In addition to the social and emotional needs of wellbeing, the psychological needs of carers, including the ability to cope with the experience of the cared for persons condition and its consequences, are also important in maintaining wellbeing of carers.

The Australian Unity Wellbeing Index defines personal wellbeing as a state of mind that comes from a long-lasting, deep sense of personal contentment (often described as subjective wellbeing). Subjective wellbeing is extremely resilient and allows us to hold ourselves steady, even during challenging times. The Personal Wellbeing Index (PWI) is based on the theory of homeostasis which maintains that people have an inbuilt mechanism that helps them recover their positive wellbeing after adversity. However, when negative life experiences reach chronic levels over time our resources (internal and external) can become depleted and subjective wellbeing may change, often leading to depression.

Impacts on carers:

Research both within Australia and Internationally provides compelling evidence about the impact of caring on personal wellbeing (see Hill and Broady, 2019).

The 2007 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.

In a more recent National Carer Survey conducted by Carers NSW in 2020 the results also showed that in all of the seven domains measuring satisfaction with life (Standard of living, Health, Achieving in life, Personal

relationships, Personal safety, Community connectedness and Future security), carers on average scored many points less than the general population. For the overall PWI, carers scored 18.2% percentage points lower than for the general Australian population.

Findings in a yet to be published needs assessment by Capital Health Network from this year confirm these same impacts on carer wellbeing are occurring in the ACT community. They found PWI scores for carers here in the ACT were particularly low with regards to satisfaction with their own health, satisfaction with what they are achieving in life and in their life as a whole. Carers who provide care for those with autism and mental health conditions in the ACT scored notably lower in their PWI's when compared to other carers.

Some 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.

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.

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.

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.

Loss of opportunity

- 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.

Research into carer wellbeing shows that carers have a better quality of life when they:

- have choices
- are heard and understood
- feel connected to the community
- make meaning from their role
- have opportunities to fulfil desired roles in life
- feel that the work they do is valued and recognised
- have the physical and emotional resources to undertake the role of caring
- have the information they require to understand and manage the care recipients' condition and needs

Research also demonstrates that when a carer's quality of life is good their capacity to undertake their caring role is increased. This in turn has positive effects for the care recipient and for the community and is reflected in:

- More effective use of existing support systems
- Better management of care recipient health requirements
- Increased ability for the carer to engage in activities outside of the caring role
- Improved carer health.

Guiding Principles:

One of the difficulties in improving the lives of carers is that often carers don't identify themselves in this way. Instead, they consider themselves by the role they have in the family system, such as wife, husband, son etc. Often there is a sense of duty or obligation to fulfil the needs of the care recipient, sometimes at the detriment to their own physical, mental and emotional health.

We acknowledge the complexity and diversity of care relationships and recognise that a care relationship is interdependent, it involves reciprocity and that any given time the care relationship is subject to the degree of reciprocity, current dynamics, personal and family history and cultural context.

A key factor in maintaining a sense of wellbeing is for people to feel that they have control over their lives. For some carers taking on the role of carer is not seen as a choice, but rather a requirement. This lack of choice can result in a negative experience of caring.

We aim to help carers reconcile the caring role and to assist them to find meaning in what they do for as long as they wish to and to support carers when it is time to leave their caring role. We also aim to empower carers so that they feel heard and understood in their caring role and have the ability to challenge the system as required.

For many carers there are several barriers to accessing services. Seeking help and support may be a sign of not coping, failure or 'admitting defeat'. Carers may be reluctant to go outside the immediate family or they may feel that there is a lack of support services available specifically for them, or that their need is not significant compared with others.

We acknowledge the need to promote the role of caring and to raise awareness of supports available throughout the community. We aim to intervene early in the carers experience of caring to provide information and services which meet their practical support needs and their social and emotional wellbeing needs to minimise the risk of carer burnout.

Carers and care relationships are different and diverse. It is important to acknowledge that for different cultural groups what is required to maintain personal wellbeing may be different and needs to be considered on an individual basis.

We aim to build a more diverse, equal and inclusive community in which all carers can live, work, socialise and care equally.

As part of our commitment to reconciliation we will work with Aboriginal and Torres Strait Islander carers to ensure they have a voice in informing how carer services are delivered and to reduce barriers to ensure Aboriginal and Torres Strait Islander peoples have access to services, information and supports that are culturally appropriate and that meet their needs.

Our commitment to carers:

Carers ACT aims work in partnership with carers to assist them to:

- be independent
- be able to problem solve
- build a sense of self-efficacy

In our work with carers, we will deliver services that:

- address the presenting problem and work to identify and resolve underlying contributing factors
- seek ways to build carer capacity
- are timely and aligned to identified needs and agreed goals
- are high quality and evidence based

Carers ACT will also work with government and community to:

- improve understanding of the key role carers have in the care-recipients health and wellbeing
- ensure that carers are recognised and considered as active stakeholders in decision-making processes
- provide inclusive services that support the informal carers to maintain their own wellbeing and to undertake their caring role.

Measuring success

In developing the framework for Carer Support the following indicators apply:

Support

- Carers have the information and resources they require to support them in their caring role.
- Carers access existing community supports through provision of information, referrals to appropriate services and case management as indicated.
- The wellbeing of carers is supported, enabling them to experience good physical and mental health which is not at detriment due to their caring role.
- Carers have access to education and opportunities to build skills and increase capacity to manage the caring role.
- Carers have access to practical supports which assist the Carer to reduce their caring load at times of high stress and to enable the Carer to participate in valued activities.

Connect

- Carers are fully engaged and valued members of the community.
- Carers participate in everyday activities such as employment, education and social activities without disadvantage.
- Carers are not isolated as a result of their caring role.
- Carers feel part of their community.
- Carers are linked to government services.
- Carers are connected to their peers.

Empower

- Carers are recognised for their role in the lives of the people they care for and are considered in the planning and decision-making processes that affect them and the people they care for.
- Carers are heard and understood in the community and by government and are encouraged to contribute and engage at all levels of the system.

SUBMISSION TO CARERS RECOGNITION ACT 2021

Carers ACT, as the leading body representing carers in the ACT, welcomes the Bill, introduced by MLA Suzanne Orr, to recognise carers through the Carer Recognition Act. Having carers recognised in this way is a significant step to acknowledging the contribution they make to the community and increasing the supports, recognition and inclusion they deserve.

There are more than 50,000 carers in the ACT with the number increasing yearly. Carers provide personal care, support, and assistance to people with disability, medical conditions (including terminal or chronic illness), mental health conditions and those who are frail aged. Carers can be family members, friends, relatives, siblings, or neighbours. We are pleased that this Act also recognises foster and kinship carers.

Carers ACT works 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. We believe that having a Carers Recognition Act will help carers to feel valued and supported in the community and will in turn improve their health and wellbeing.

Carers ACT is supportive of the construct and content of the Act. We appreciate and value the acknowledgment that caring exists within a relationship and that it is important that the rights and needs of both people are acknowledged and upheld to support that relationship. We support the objects of the Act and the care relationship principles.

We are supportive that the Act has strengthened the context by which organisations will be accountable for how they treat carers and includes not only carer specific agencies but also other services and agencies that interact with carers.

Carers ACT also welcomes the way the Act will be enforced via a new obligation to make an annual report, which must be publicly available, addressing how organisations met their carer requirements according to the Act. The proposed template, which will contain minimum data requirements, will be important to enabling simple recording for both government and non-government organisations on how well the community is in delivering carer supports.

Carers ACT supports the inclusion of the need to consult with carers, or an entity representing carers when planning or reviewing supports. We would like to identify that this requirement will need to be supported with financial supports to enable carers and/or carer entities to participate in such consultation. This includes the resources to cover the cost of replacement care to enable attendance and participation for individual carers and resources for organisations to provide input in the case of an entity representing carers. Without this it will be easy to exclude the voices of some carers or undertake tokenistic consultation.

Carers ACT have consulted with Carers within the ACT regarding their thoughts about the Act and these are very positive, and carers are grateful for the acknowledgement. Through an online voting poll more than 99% of carers indicated support for the Act. We also received feedback from carers through a range of consultation mechanisms.

Whilst overall supportive, carers did raise the following issues with how the act may be interpreted including:

- Carers queried whether the Act was strong enough to ensure recognition about the multiple caring roles of many carers.

- Carers commented that often organisations fail to see their individual needs outside of their needs as a “carer” or their needs within a “caring role”. Rarely do organisations acknowledge the carer as an individual with their own needs (such as health care for example) often presuming their needs are solely based only around the perceived needs of their caring role (need for respite for example). Carers would like to see that organisations are also able to see them as an individual and address their needs as such.
- Carer’s leave was a significant issue in the specific consultation regarding the recognition Act. Carers expressed not feeling they could ask for carers leave, even if available, in the workplace. This was due to the general stigma carers experience regarding the time off work that may be required to tend to their cared for person. Greater acknowledgement and understanding of the important work carers do will help with this. However, carers report that they continue to be viewed as unreliable by some managers and employers. Carers describe fighting for flex leave, in some cases unsuccessfully, and the general need to use personal or long service leave to maintain their caring role. For many carers this was their most pressing issue, and they hope the Act will help to address this on both a practical and societal level.
- While being grateful to be recognised by this Act, foster and kinship carers queried how their caring role will be interpreted given they are classified as ‘volunteers’ for some regulations within Out of Home Care, and ‘workers’ for others. This group of carers have another set of distinct needs as a group and of course as individuals. It would be useful for involved organisations to discuss these issues further before finalising the Act.
- Carers in the mental health space expressed concern about making sure that carers of people with ‘mental disorders’ and ‘mental illnesses’ as described in the Mental Health Act 2015 are both included, accounting for the understanding that the perceived care needs of certain groups can be more or less than others. Carers are eager to see the episodic nature of caring as related to the episodic nature of mental health (and other) conditions recognised as a valid form of caring with separate demands. There is a need for understanding of individual circumstances being more important than blanket policies attributed to classifications of disorders.

Championing the act

This legislation is very welcome, and Carers ACT will have no reservations in supporting it. The interpretation of the legislation, while it is undoubtedly clearer than most, may leave some ambiguity, particularly around how and what is ‘recognised’ in terms of carer recognition and how and what ‘support’ looks like. In real life examples, being told to approach one’s EAP, for example, can be viewed as offering support by an employer when this is something employees are generally already aware of. Equally stating, ‘I recognise this is a difficult situation for you, but I have other staff to think of’, is also technically recognising a carers situation. Both examples are not the intent of the Act, as we understand it, but are the experiences of carers currently.

To ensure the spirit of the Bill is furthered it will take willing champions beyond just those within Carers ACT and carers themselves. It will take government and non-government organisations alike to make more deliberate consideration of what they could do to assist carers they support, in the work they do for carers, and in working alongside carers as employees.

While the majority of organisations will support this Bill there will inevitably be some reluctance regarding the time involved in completing the new reporting safeguards that will be required. From a change in perspective this can be viewed as upholding best practice in customer service and employee relations. It has been raised

by organisations to Carers ACT that there are concerns that carers rights may be held up as more 'important' than the rights of the vulnerable people they care for. This is not the message of the Bill, as we understand it, and in championing the Bill this is a concern that will have to be addressed. In the Human Rights Jurisdiction of ACT, we should be

concerned about all people's rights and never should one group be valued above another. It would be expected that the most vulnerable members of society would not be disadvantaged by the adoption of better practices in recognising the needs of others.

Defining carers

This is an ongoing debate regarding the definition of carers and how they should be named and recognised. The term 'carer' is the preference of many. This word has been diluted by the support worker industry who now also call themselves carers, which now requires us as a carer organisation to use the term 'unpaid carer' to differentiate between carers and support workers. Another viewpoint is that, culturally, some carers do not accept that their caring role amounts to any more than what is required of a member of the family, and indeed sometimes of a friend or neighbour, no matter how much they may be needed to provide care. In this instance it is difficult to get supports to these groups of 'unofficial carers'. This remains a stumbling block to accessing supports for this unseen group and therefore this Act will struggle to be applied to this group. This will be a challenge to all involved organisations.

The term isn't the important thing. The recognition that carers exist, no matter how they choose to be acknowledged, and that the support they need is there when they need it is the important factor. It is hoped that while unpaid caring work is more actively recognised, the term by which families do it will be irrelevant, to ensuring they get the help they need, when they need it.

The personal cost of caring

The reality for many carers is that they, lose their jobs, give up unrealistic expectations of keeping a job while caring, or burn out trying to do both. These are known facts. Caring is a hard road that not all carers feel they have a choice in taking. That is not to say caring cannot be rewarding, and life changing, as many carers tell us it is. The constant struggle to advocate for the person they care for often leaves no time or energy for carers to care for themselves creating high incidences of chronic conditions among carers. If this Act can go even part way to alleviating some of these social, physical, emotional, and financial costs it will be successful and worthwhile.

Recognition

Carers have informed Carers ACT in recent years of the value they set upon their experience and having their voice heard, and represented, within the arenas in which decisions are being made. While Carers ACT does this work and assists carers who are willing to volunteer their time to do this work, there are other opportunities to involve carers in ways that matter. Carers ACT have worked alongside carers in deliberative democracy processes which enable carer voices to be truly heard and to have input into every stage of project development into plans that will affect them. It is not unusual currently to have carer input into the later stages of a project. It is more unusual to ask carers for feedback about ongoing projects in order to improve

upon them, or to be consulted about what they would like to see developed, or to involve carers in the various all the steps towards those projects.

Conclusion

Carers ACT and the vast majority of carers in the ACT support the proposed Carer Recognition Act. We are pleased to see the value and worth of carers being recognised and believe that the Act will assist in ensuring that we continue to build a Canberra that Cares for Carers.

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