



Submission to the Review of the Carers Recognition Act 2004

August 2018

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

P: 1300 227 377 W: www.carerswa.asn.au E: policy@carerswa.asn.au

ABOUT CARERS WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have disability, mental illness, a chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location. Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A report undertaken by Deloitte, Access Economics, 'The economic value of unpaid care in Australia in 2015', determined the replacement value of the care undertaken by carers in Australia to be \$60.3 billion per annum.

Some important facts about carers include:

- There are 2.7 million unpaid carers in Australia. More than 856,000 carers are primary carers.
- There are more than 320,000 family and friends in a caring role in Western Australia or approximately 1 in 8 in the community.

ENQUIRIES

Paul Coates
Chief Executive Officer

Carers WA
182 Lord Street
PERTH WA 6000

Phone: 1300 227 377

Email: paul.coates@carerswa.asn.au

Introduction

Carers WA appreciates the opportunity to contribute to the Review of the *Carers Recognition Act 2004* (the Act). Carers WA played a pivotal role in the introduction of the Act and acknowledges the dedication of a large number of carers who lobbied for this recognition over a number of years. WA had the distinction of passing the first carers recognition legislation in Australia and the then government is to be congratulated for its progressive approach.

For the past 14 years the Act has been an important mechanism for promoting the recognition of carers. The Act has been used by carers, advocacy groups, peak bodies and service providers to continue to encourage the consideration of unpaid carers in policy and service delivery settings.

2008 Review of the Act

A review of the Act was undertaken in 2008 as required by the legislation, however the recommendations of this review were not fully implemented. The recommendations of the 2008 review remain relevant and should be considered in the current review.

Impact of the Act

The Department of Communities (formerly the Department of Local Government and Communities) is responsible for administering the Act and has worked with Carers WA and carer representatives to develop the WA Carers Strategy (the Strategy). The Act together with the Strategy combine to continue to recognise and improve the lives of carers in the community. Carers WA regularly writes submissions on policies and plans citing the Act as a reminder to agencies of their obligations under the Carers Charter. The Act is also used by carer representatives who are recruited and trained to represent carers on committees and working groups within the health and mental health sectors. Carer representatives make members of these committees aware of the need to comply with the Act.

Carers generally acknowledge that recognition of their role has improved since the introduction of the Act. Carers do, however, report that this progress has been slow and that there is still a lack of knowledge about the Act. They continue to feel that their role is not acknowledged and that an understanding of the Carers Charter is not demonstrated in the actions of public sector agencies. This occurs in both the health and disability sectors as well as in many other areas of carers' lives.

The following carer stories provide an example of the successful application of the Act, and a scenario where the Act was not applied. Carers WA hears many stories illustrating that the Act is not being adequately applied.

Jane and Phil's Story

Jane and her husband Phil became carers for Phil's mother, Gwen, as she aged. Gwen's husband had passed away and she purchased a unit near Jane and Phil. Gwen was not happy in her new home and Jane began to wonder if she had depression. An ACAT assessment was arranged through the GP, which concluded that Gwen needed some social support and services were put in place. Gwen showed some initial improvement, but soon deteriorated very quickly and began to have panic attacks. She would call the ambulance at odd hours during the night and rang Phil's mobile up to 30 phone times per day. She began having episodes that Jane and Phil did not understand which caused them stress, waiting for the inevitable phone call at all hours.

Eventually, Gwen ended up in emergency. During this hospital visit, a social worker & psychiatrist came to speak with Jane and Phil. They talked about Gwen's deteriorating health and asked about changes in her behaviour. They informed Jane and Phil in a respectful manner that Gwen had dementia, which was the cause of her challenging behaviour and that sadly, it would keep getting worse. They recommended that Jane and Phil consider what was best for Gwen. They suggested that she would very quickly need 24/7 care and that Jane and Phil would not be able to provide this.

The medical staff were kind, compassionate & slowly helped Jane and Phil realise the implications of the situation. They assisted them to put in place the care Gwen needed. They provided information on a nearby aged care facility and set up an appointment for Jane and Phil to visit and talk with the staff.

Jane says "They provided a great example of respecting the patient, and us as carers. They engaged with us and chatted about what was best for Mum & best for us too. They were kind, respectful, informative and very helpful."

Narelle's experience

Narelle is a long-term carer for her brother Robert who has an intellectual disability, dysphagia, limited verbal communication and high care needs. Robert lives in Disability Supported Accommodation and has recently been admitted to hospital a number of times. During the latest admission for aspiration pneumonia, Narelle visited Robert each day during which time he looked unwell, was hot to touch and sweating and was on oxygen and IV antibiotics. On the third day Narelle was concerned about his condition and told the nurse that he still did not look well. During this visit Narelle had several conversations with the nurse and the pharmacist about medication delivery. Narelle left the hospital in the afternoon shortly after the morning staff nurse handed over to the afternoon staff outside of Robert's room; there was no indication that Robert would be going home.

That evening Narelle received a call from the hospital and was told that Robert was going home by ambulance. Narelle asked if the accommodation staff had been informed. The hospital staff said no and said they would ring in a few minutes. It became apparent to Narelle that the ambulance had already arrived at the hospital to pick Robert up and she explained that the staff at his accommodation require notice of Roberts arrival to ensure adequate staffing as there are multiple residents with high care needs at the accommodation. The hospital called Narelle back a few minutes later and said that no-one was answering at Robert's accommodation but they would keep trying (despite Narelle offering to call for them). Thirty minutes later the nurse at Robert's home called Narelle and said that Robert had arrived with no notice and with no antibiotics for his infection, which they would not be able to obtain from the pharmacy until the next day. She noted that if they had been given prior notice the staff could have picked Robert up and taken him home.

This apparent lack of consultation with the carer in discharge planning resulted in Robert missing a dose of antibiotics, arriving home unexpectedly to understaffed accommodation and having to pay for transportation by ambulance. While the nursing staff had informed Narelle of the situation, it was too late for her to provide advice and the staff did not acknowledge her position as a partner in the care of her brother.

Recommended reforms to the Act

In order to improve the efficacy of the Act, Carers WA recommends the following changes be implemented.

1. Object of the Act

The Act is limited by its relatively narrow object. The purpose pursued by Carers WA as the peak body for carers in the state is to work to:

- Improve the health, wellbeing, resilience and financial security of carers.
- Ensure that caring is a shared responsibility of family, community and government.

It is recommended that the object of the Act be extended to include the wider sentiments expressed above. The object should read as follows:

- a) To recognise the role of carers in the community.
- b) To provide a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers.
- c) To promote improved health, wellbeing, resilience and financial security of carers.
- d) Ensure that caring is a shared responsibility of family, community and government.

2. Extension of the Act to cover all State Government Agencies

Carers interact with many public services organisations in their caring role. These agencies can fail to acknowledge carers and can implement policies and processes which make life more difficult for carers. It is recommended that the Act be extended to a wider range of public service agencies including, but not limited to, the Department of Education, Department of Housing, Department of Communities, Department of Justice, Western Australia Police, Department of Local Government, Sport and Cultural Industries and the Office of the Public Advocate.

The most comprehensive approach to this issue would be the inclusion of all State Government Agencies and their funded contractors. Agencies could be divided into two groups as per the Commonwealth *Carer Recognition Act 2010*. The first set of agencies would be obliged to take all practicable measures to ensure employees and contractors are aware of the Act and its object. A more narrow set of defined Agencies would be obliged to comply with the Act through reporting to the Carers Advisory Council. It is suggested these agencies include the:

- Department of Health;
- Mental Health Commission;
- Department of Communities; and
- Department of Education

Lynne's story below illustrates how the life of a carer could be improved by recognition and understanding from a wider ranges of public sector agencies.

Lynne's Story

Lynne has been caring for her husband Greg since 2007. Greg has an acquired brain injury and has high support needs. Greg and Lynne have a 12 year old daughter Megan. In many instances, the community does not recognise the support Lynne provides to Greg as he lives in supported accommodation. However, since his accident Lynne has managed all Greg's financial, housing, therapy and medical needs as well as acting as Greg's advocate in many situations where he can no longer advocate for himself.

In the course of providing care, Lynne interacts with a variety of government departments and private agencies on Greg's behalf and she believes that her role is underestimated, minimised and misunderstood. These agencies and organisations include banks, private therapy providers, the Office of the Public Advocate, the Department of Housing and the Department of Justice. Despite not living with Greg Lynne has sacrificed employment opportunities and self-care in the ongoing effort to ensure Greg is well cared for.

3. Consideration of carers as employees

Carers have unique challenges as employees. Balancing caring responsibilities with paid work can be difficult. Current human resource legislation (Commonwealth *Fair Work Act 2009*) sets out minimum leave entitlements for carers. These entitlements do allow the use of personal leave to cover caring responsibilities. However, carers leave is taken out of sick leave and is not a separate entitlement. The minimum requirements also provide opportunities for consideration of flexible working hours for employees in a caring role, however, an employer is not required to accept proposals for flexibility.

Carers often report running out of leave entitlements and being forced to reduce working hours or resign. When their caring role ceases or changes, carers find it difficult to increase their working hours or re-enter the labour force.

It is recommended that as well as the obligation to abide by the Carers Charter, State Government agencies should also be obliged to recognise carers in their internal human resource policies, so far as they affect the employee's caring role. It is recommended that the Act be amended to include reference to employees. Specifically, that under Part 2 – Compliance with the Carers Charter in section 6 (2) should be amended to include a new sub paragraph reading - "The applicable organisations must develop internal human resource policies supporting carers to balance their caring role with their working role".

Sarah's experience below illustrates the difficulties faced by working carers.

Sarah's experience

Sarah cares for her husband Tony, who has Parkinson's disease. Tony was diagnosed around 30 years ago and at first required little or no assistance. His needs have now increased and the journey of care has been long and complex as the disease has progressed.

Sarah has worked for a State Government Agency since 2005. During this time she accumulated a substantial amount of leave. In 2013 Tony had a brain haemorrhage which affected his cognitive function and Sarah reduced her work hours by using personal leave and long service leave to care for Tony.

In 2016 Tony experienced a significant deterioration in his condition. Sarah stopped working to provide full time care for Tony. She used further long service leave and personal leave. By October 2016 Sarah had exhausted all leave entitlements and applied for and was granted 12 months leave without pay. In July 2017 Sarah and Tony moved from regional WA to Perth as Tony's medical needs increased. Sarah's applied for and was granted a transfer to a metropolitan office. When her 12 months leave without pay ended Sarah applied for further leave and was granted another six weeks.

Since this time, Sarah has experienced difficulties in ascertaining what her rights are and has felt pressured to "do the right thing" and resign rather than continuing on leave without pay. Sarah is 61 and will not be eligible for an age pension until 66 and a half. She would therefore need to apply for unemployment benefits for a number of years. Tony's condition is unpredictable and although the ultimate outcome is clear, the timing is not known. At some point Tony may require residential care which will be costly. Sarah receives the carer payment but will no longer be eligible for this if/when her caring role ends leaving her with few resources as retirement age approaches. The uncertainty around her employment situation and the correspondence from different parts of government providing contradictory information has exacerbated an already stressful situation. Some letters strongly suggested that the government has been very generous and she needed to make a decision about her working future. Eventually Sarah successfully negotiated indefinite leave from her Department. However, she believes others in a similar situation may not have the knowledge, resilience or resources to advocate for themselves and may be forced to resign their position.

4. Compliance and reporting

Service providers in the health and disability sectors note that current reporting requirements under the Act are onerous. Similarly the Carers Advisory Council, which is made up of volunteer carers from the community, report that the task of reviewing these reports and compiling a compliance report is time-consuming and complex. This compliance report is prepared for the Minister and is subsequently tabled in Parliament.

In line with the State government priority of reducing red tape, it is recommended that the compliance and reporting process for the Act be simplified. Compliance reporting should be carried out by an independent and professionally accredited agency rather than a voluntary group. For example, compliance with the Act could be tested as part of a cyclical audit carried out by the office of the Auditor General.

It should also be noted that current reporting consists of each agency responding to a series of questions about how they comply with the Carers Charter. These reports do not cover non-compliance with the Act or reporting of complaints and issues raised by carers. It is recommended that to supplement a cyclical audit, a survey of carers is undertaken to collect user perceptions of agency compliance with the Act.

5. Role of the Carers Advisory Council

As has been previously noted, the Carers Advisory Council is made up of volunteer carers from the community. The compliance role undertaken by the Carers Advisory Council has been difficult for members to manage and is an inappropriate level of responsibility for such a group. It is recommended under Part 3 – Carers Advisory Council in section 10, the role of the Carers Advisory Council in preparing compliance reports be removed and replaced with a role consistent with monitoring the audit and carer survey suggested above as well as providing general feedback to the Minister.

It is also noted that membership of the Carers Advisory Council does not include any link with Carers WA as the peak body for carers in Western Australia. Carers have suggested that there should be a formal link between the Carers Advisory Council and Carers WA.

6. Awareness and education campaign

Carers WA receives consistent feedback that there is a lack of awareness, among both carers and agencies, of the Act and its purpose. Following this review it is recommended that a campaign be implemented to raise awareness of the Act and the recognition of carers in the community. Carers WA would provide assistance in the delivery of this awareness and education.

Further considerations

The national policy shift to consumer directed care with the introduction of both the National Disability insurance Scheme (NDIS) and the Commonwealth Home Support Program (CHSP) has altered the care landscape in Australia. Into the future, provision of many disability and care services will be delivered through packages funded by the Commonwealth. Providers, previously funded through State disability and health agencies and bound to comply with the Act, will no longer fall under this legislation. Consideration

should be given in this review to clarify how these service providers will continue to recognise carers and their important role.

Summary of Recommendations

In summary, Carers WA recommends that:

- The Object of the Act be extended to reflect a wider recognition of carers.
- All State Government agencies be obligated to comply with the Act.
- Consideration of carers as employees of agencies be included in the Act.
- Reporting and compliance requirements be simplified with compliance auditing carried out by an independent and professionally accredited agency.
- The Carers Advisory Council take on a monitoring rather than a compliance role.
- Following the review of the Act, an awareness and education campaign on the Carers Charter and compliance requirements be implemented.
- The review should take into account changes in national policy and funding arrangements and clarify the role of state and commonwealth legislation in carer recognition within disability and aged care services.