

**Submission  
No 170**

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO  
HEALTH AND HOSPITAL SERVICES IN RURAL,  
REGIONAL AND REMOTE NEW SOUTH WALES**

**Organisation:** Carers NSW Australia

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Parliament of New South Wales  
Portfolio Committee No. 2 – Health  
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To whom it may concern,

Carers NSW welcomes the opportunity to provide a submission to the Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales. This submission will focus on the unique challenges faced by family and friend carers when accessing health and hospital services, and will emphasise the need to improve the accessibility of these services in regional, rural and remote areas to support carer health and wellbeing.

### About Carers NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

### Carers and the health care system

Carers access health services both as patients themselves and with and on behalf of the people they care for. In both cases, health services can be complicated to access and may not meet patients' needs. Many patients rely on family members and friends to assist them in accessing health services, and many more are discharged into the care of carers at home and in the community. Carer-inclusive health services are critical in sustaining informal caring arrangements and supporting carer health and wellbeing.

In addition, the NSW Carers Charter stipulates that carers are partners in care, and their choices, views and needs should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.<sup>1</sup> As such, carers require increased support, information and resources to better navigate the health system in support of the person they care for.

Carers are known to neglect their own health care due to prioritising the health care of those they care for, and this along with the physical and emotional challenges of caring results in a higher than average

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<sup>1</sup> Carers (Recognition) Act 2010, Schedule 1 NSW Carers Charter

rate of disability, chronic health conditions and emotional distress.<sup>2</sup> The health and wellbeing of carers is imperative to the social and economic sustainability of care in the home and community, as when carer health and wellbeing is at risk, there is a greater chance of carers losing the capacity to care or being absent from the home to engage in treatment. The temporary or permanent reduction in capacity to care has an impact at the individual, community and sector levels, including implications for personal relationships, community and health services, and health budgets.

### Carers in regional and rural areas

Of the estimated 854,300 carers living in NSW, nearly 30 per cent live in rural or regional areas.<sup>3</sup> Caring occurs at much higher rates in rural and regional areas, with approximately one in seven people providing care, as opposed to one in ten in metropolitan areas. Rates of disability and chronic health conditions are higher in rural and remote areas, increasing the need for informal carers.<sup>4</sup> It is also important to note that Aboriginal and Torres Strait Islander people in rural and regional areas are particularly likely to have one or more caring role, with more than one in three caring in these communities.<sup>5</sup>

The higher incidence of disability and chronic health conditions in rural and remote areas also means that carers living in these areas also experience disability and chronic health conditions at higher rates compared to carers living in metropolitan areas.<sup>6</sup> The poorer health and wellbeing of non-metropolitan carers is often attributed to limited supply and reach of services such as respite, increased isolation, and the tendency for such carers to have fewer informal networks to provide additional support.<sup>7</sup>

Despite the proportionately higher rates of disability and chronic health conditions in rural and remote areas, health care and community services are not distributed accordingly. The 2020 National Carer Survey<sup>8</sup> found that many regional and rural carers in NSW reported they were not able to access services required by the person they care for in their local area. Furthermore, many regional and rural carers reported that carer-specific support services are not available locally.

In addition, many carers experience financial hardship due to limited income and the additional costs associated with their caring role; as such, addressing carer finances has been identified as a priority in the new NSW Carer Strategy: *Caring in NSW 2020 - 2030*. For rural and regional carers, these costs are often even greater due to the need to travel long distances to access services and supports.

The recently conducted Carers NSW 2020 National Carer Survey found that more than half of regional and rural respondents experienced at least one form of financial stress in their household in the year

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<sup>2</sup> Carers NSW (2020) *Carers NSW 2020 Carer Survey: Summary report*, Carers NSW, North Sydney.

<sup>3</sup> Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Summary 2018*, New South Wales, Catalogue no. 4430.0, Canberra.

<sup>4</sup> Australian Institute of Health and Welfare (2018) *Australia's Health 2018: In brief*, <https://www.aihw.gov.au/reports/australias-health/australias-health-2018/contents/table-of-contents>, viewed 13 December 2018.

<sup>5</sup> Australian Bureau of Statistics (2016), National Aboriginal and Torres Strait Islander Social Survey 2014-15, Cat. No. 4714.0, available online at <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Main%20Features~Key%20findings~1>, last updated 3 October 2019.

<sup>6</sup> Edwards, B., Gray, M., Baxter, J. and Hunter, B. (2009), *The tyranny of distance? Carers in regional and remote areas of Australia*, Prepared for Carers Australia by the Australian Institute of Family Studies.

<sup>7</sup> Winterton, R. and Warburton, J. (2011), 'Models of care for socially isolated older rural carers: barriers and implications', *Rural and Remote Health* (online) vol. 11, no. 1678.

<sup>8</sup> Carers NSW (2020a).

prior to completing the Survey, compared to just over one in five Australian households. More than one in eight (12.7%) of carers living in regional and rural NSW reported that they had experienced more than 4 instances of financial stress in their household in the prior 12 months, and were therefore considered to have been in financial distress. While many carers reported experiencing financial stressors in the Survey, inner regional carers reported the highest rate of financial distress of all.

Many services are centralised in regional centres and major cities, and inadequate or inaccessible public transport infrastructure often requires carers to drive vast distances to access the services they and the person they care for require.<sup>9</sup> Not only is this time-consuming, but carers in non-metropolitan areas are more likely than those in metropolitan areas to find transport costs to be an added financial burden.<sup>10</sup> Where schemes do not adequately cover carer and care recipient transport, carers often have no choice to meet these costs, or forego the services and supports needed to maintain their own health and wellbeing or that of their care recipient.

The 2020 National Carer Survey found that while most carers accessing public and primary health care services with their care recipients were included in decision making, a minority were asked about their own needs. As a result, many carers reported that these services did not really assist them to achieve their own needs and goals, such as taking a break from the caring role, attending to their own health and wellbeing, or increasing their engagement in the workforce.<sup>11</sup>

### Identification of carers' health needs when presenting with a patient

NSW Health's Information Bulletin, 'Identifying the Carer at Patient Registration' acknowledges carers are more likely to experience physical and mental ill health and disability than the general population. When a carer presents to a health service for the person they care for, carers may not discuss their wellbeing unless practitioners specifically ask. While NSW Health continues to implement new measures to collect carer information, Carers NSW believes more can be done to proactively identify carer health needs and connect carers with the treatment they require. One way to encourage this is through inclusion of carers in local health district (LHD) Health Care Services Plans, which identify groups at higher risk than the remaining population of poor health.

Another potential solution is for carer health checks, which Carers NSW has recommended in a number of Pre-Budget Submissions to the NSW Government.<sup>12</sup> Free carer health checks are routinely delivered in a range of settings in the UK, including in the home and at pharmacies, community care centres, sports centres and GP practices. Nurses and other health workers conduct assessments of a carer's physical health including BMI, blood pressure, cholesterol and blood sugar as well as mental health assessments.<sup>13</sup> Evaluation data indicates that health checks led to sustained self-care and healthier behaviours for many carers.<sup>14</sup> Carers reported these checks are an opportunity to attend to

<sup>9</sup> Peel, N., Westmoreland, J. and Steinberg, M. (2002) 'Transport safety for older people: A study of their experiences, perceptions and management needs', *Injury Control and Safety Promotion*, vol. 9, no.1, pp. 19-24.

<sup>10</sup> Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Gallego, G., Lincoln, M., Brentnall, J. and Griffiths, S. (2013) 'Addressing the barriers to accessing therapy services in rural and remote areas', *Disability and Rehabilitation*, vol. 35, no. 18, pp. 1564-1570; Carers NSW (2014) *Carers Survey: Main Report*, Sydney; Schirmer (2017).

<sup>11</sup> Carers NSW (2020a).

<sup>12</sup> E.g. Carers NSW (2020) *Caring through crisis: Carers NSW Pre-Budget Submission 2021-22*, Carers NSW, North Sydney.

<sup>13</sup> Keesing, S., Rosenwax, L. and McNamara, B. (2011) "Doubly deprived": a post-death qualitative study of primary carers of people who died in Western Australia', *Health and Social Care in the Community*, vol. 19, issue 6, pp. 636-644.

<sup>14</sup> Yeandle, S. and Wigfield, A. (2011), *New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme*, Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Leeds, available online at:

their own health needs, and increase awareness of health issues and motivation to follow up with referrals for specialist treatment.<sup>15</sup> Carers also identified benefits to their psychological wellbeing and recognition of the demands of their caring role.<sup>16</sup>

Carers NSW believes that Community Health Nurses are best placed to conduct the health checks, working closely with other health professionals in order to identify carers through existing clients of services such as the LHD carer programs, Chronic Disease Management Program (CDMP), the Family and Mental Health Carer Program and the Grief and Loss Service. In addition to physical and psychological assessments, carer health checks would also provide an opportunity for Community Health Nurses to refer carers to existing carer supports and services.

Carers NSW envisages significant savings to the health budget with the implementation of holistic health care checks for carers. Identifying and treating physical and mental health conditions are likely to improve carer wellbeing overall, reducing the likelihood of chronic conditions developing and their associated complications which require extensive medical intervention or hospitalisation.

### Expanding provision of carer spaces in hospitals

Family members and carers provide critical informal support and assistance during a hospital stay. Carers can provide reassurance and support to the patient, facilitate communication with health professionals, support the delivery of optimal, person-centred health care, act as an advocate, monitor health care treatment and compliance, and may assist with practical tasks such as feeding and showering. Carers' contribution to the care of the patient often has a direct benefit to hospital staff, can reduce admission timeframes and has overall economic benefits for NSW Health. Despite these benefits, most hospital spaces are not well designed to accommodate carers in the short or longer term.

In an attempt to assess the need for carer-friendly spaces, Western Sydney LHD conducted a survey with Nurse Unit Managers across ten wards in a major metropolitan hospital. The survey found that between 2014 and 2015, an estimated 477 patients had a family member or carer stay overnight, with a total of 3070 overnight stays.<sup>17</sup> Whilst some accompanied patients in single rooms, family members and carers often slept in chairs next to patients in shared rooms.<sup>18</sup> The estimated average length of stay was four days, with the longest stay being over 30 days. This LHD found that having a family member or carer stay overnight benefits the patient, family member or carer and staff.

This evidence is consistent with reports to Carers NSW of the care provided to care recipients when in hospital. Hospital admissions may be one off and a period of crisis for carers, or may be chronic with issues compounding as carers sacrifice their sleep and comfort to support their family member, partner or friend. Carers report that accommodation is prioritised within acute care settings; the chronicity of admissions should also be considered when establishing better accommodation for carers in hospital settings. Particular consideration should be given to carers from a regional or rural and remote location, and in cases where a patient has become palliative. Designated carer spaces and flexible working hours

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<http://www.sociology.leeds.ac.uk/assets/files/Circle/151111-circle-newapproaches-report-summary.pdf>, viewed 28 August 2019.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> Research undertaken by Western Sydney Local Health District Patient and Consumer Experience Team (2015).

<sup>18</sup> Ibid.

remove unnecessary pressure from carers who are required to support their loved one in hospital. Cultural needs and expectations may further impact on the admission experiences of carers.

Carers NSW commends the inclusion of 'carer zones' in recent Bankstown and Westmead hospital developments in metropolitan Sydney, and the implementation of a 'gathering space' for Aboriginal family members to collect as a group and discuss treatment and holistic care needs with the medical team. As regional, rural and remote LHDs maintain and redevelop their buildings, something that received substantial funding in the recently delivered 2020-21 NSW State Budget,<sup>19</sup> Carers NSW recommends similar initiatives be scoped and implemented to meet the needs of carers in these areas.

### Carer involvement in palliative care

The Groundswell Project<sup>20</sup> on death and dying found that nearly half of all Australians have provided emotional support or been involved in caring for someone who is dying. More than 50% of people know someone who has been an end of life carer. In addition, only 20% of people know how to navigate the health system to support a dying person and less than 40% know where to get information about carer support.

Carers who provide support to a person at the end of their life often provide this care under challenging circumstances which impact their own health and wellbeing. Due to the progressive nature of many life limiting illnesses, carers will often find that their caring role will become increasingly complex and physically demanding as the illness progresses, often without access to training or advice on the practicalities of providing care safely. This can contribute to increased stress and risk of personal injury and chronic illness.

To ensure carers are able to carry out their caring role safely and with confidence, Carers NSW advocates that carers be given opportunities to be involved and considered in care and treatment plans alongside the care recipient and in consultation with health professionals. Carers would also benefit from access to information relevant to their caring role including patient prognosis, care plans, discharge timelines and medication lists. When a patient becomes palliative, health professionals should ensure that carers are offered practical direction, training and support to provide care safely, and following a death, carers should be supported emotionally with access to counselling and bereavement services.

Carers NSW also recommends that carers in these situations be offered skills development opportunities to improve the safety and sustainability of caring arrangements, similar to the modules developed by Carers NSW under the Carer and Consumer Coaching (3CP) program.<sup>21</sup>

### Conclusion

The disparity experienced by people living in regional, rural and remote locations can be minimised through identification of the unique health related challenges faced by these communities. This is achieved through consultation and research to ensure health and hospital services are effectively co-designed and meet the needs of people living outside metropolitan areas, particularly where they are vulnerable to adverse health impacts.

<sup>19</sup> NSW Government (2020), 'Regional NSW', *The NSW Budget 2020 – 2021*, available online at: <https://www.budget.nsw.gov.au>, last viewed 10 December 2020.

<sup>20</sup> Noonan, K. (2020) *Death Literacy in Australia: The Groundswell Project*. Groundswell Project. Australia.

<sup>21</sup> Hofstaetter, L., Docker, M. and Hill, W. (2020), 'Protecting Health and Wellbeing in the Home: Upskilling informal carers', poster presentation delivered at the 2020 Australian Association of Gerontology Conference, 17-20 November 2020, available online at: <http://www.carersnsw.org.au/page/898>.

Carers NSW commends the Committee for reviewing the accessibility and quality of health and hospital services in regional, rural and remote areas. Carers NSW emphasises that by meeting the health needs of family and friend carers, health services will support carers in their provision of

informal support to those they are caring for. Additional focus should be paid to the unique needs of people with disability, and those who identify as Aboriginal and Torres Strait Islander, culturally and linguistically diverse or lesbian, gay, bisexual, queer, transgender and intersex (LGBTQI+), as these groups are more likely to experience compounding health factors.

Thank you for accepting our submission.

Yours sincerely,

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Carers NSW