

**Submission
No 27**

**INQUIRY INTO CURRENT AND FUTURE PROVISION OF
HEALTH SERVICES IN THE SOUTH-WEST SYDNEY
GROWTH REGION**

Organisation: Carers NSW Australia

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Parliament of New South Wales
Legislative Council Portfolio Committee No. 2 - Health
portfoliocommittee2@parliament.nsw.gov.au

Current and future provision of health services in the South-West Sydney Growth Region

Carers NSW is pleased to have the opportunity to respond to the Parliamentary Inquiry into current and future provision of health services in the South-West Sydney growth region. Carers NSW commends the Legislative Council on seeking feedback from key stakeholders to ensure that provision of health services is equitable and sufficient to meet the needs of the diverse and expanding population in the region.

This submission will explore the health needs of carers, with particular focus on the importance of carer inclusion in service provision, through recognition of the caring role and the impact of caring on carer health and wellbeing outcomes. This submission will reflect the core issues reported by carers to 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. 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.

Thank you for accepting our submission. For further information, please contact Madeleine Gearside, Policy and Development Officer at _____ or on _____

Yours sincerely

Elena Katrakis
CEO
Carers NSW

Supporting carers in the provision of health services in South-West Sydney

Background

Data from the Australian Bureau of Statistics (ABS)¹ indicates that there are approximately 132,900 carers in the South Western Sydney region². Of that number, there are an estimated 1,668 Aboriginal or Torres Strait Islander carers and 18,400 young carers (under the age of 25 years), the second largest population of young carers in NSW. In addition, an estimated 34,700 carers in South Western Sydney speak a language other than English at home, and of those, 9,300 do not speak English well. It is worth noting that this data is likely an underestimate given the high rates of caring and hidden carers in culturally and linguistically diverse communities which are overrepresented in South-West Sydney.

The Carers NSW 2018 Carer Survey³, conducted between May and July 2018, received a total of 1,830 valid responses, including 165 from the South Western Sydney Local Health District (LHD). Nearly 85% of carers responding to the survey in that region were female, with an average age of 58 years. The vast majority (90%) were the main person providing care, and approximately half of all respondents from that region reported that they had no support from other family or friends in their caring role. On average, carers responding to the survey in that region spent 83 hours per week caring, and had been caring for 14 years.

These findings reflect a female dominated informal support network, providing a significant amount of support and receiving little assistance from family members and friends in their caring role. Findings also indicate that many carers are of working age, yet are the main source of informal support for their care recipient(s), which can lead to challenges balancing care and work responsibilities. The duration and intensity of care provided in this region emphasises the degree to which carers are a support and knowledge base when their care recipients are accessing services, including health services. It is imperative that health services understand that carer inclusion in service provision impacts not only carer health and wellbeing, but also the health outcomes of the people they care for.

Just over half of carers responding to the Carers NSW 2018 Carer Survey from South Western Sydney reported that they were caring for someone under the age of 65. Around 2 in 3 carers responding reported caring for a National Disability Insurance Scheme (NDIS) participant, indicating that a high proportion of care recipients represented have a disability. Approximately 1 in 4 carers were caring for more than one person. According to the results of this survey, the profile of carers in South-West Sydney is reflective of significant diversity; nearly 30% of respondents identified with a cultural background other than 'Australian', and 1 in 3 carers spoke a language other than English. These findings are consistent with the level of diversity reported in population level statistics, and have implications for the cultural responsiveness required of health services in the region.

Key challenges

Carers responding to the Carers NSW 2018 Carer Survey from the South-West Sydney region reported encountering a number of significant challenges. These challenges, related to health, income, living expenses, recognition and mental health can directly impact the caring relationship and access to health services. They include the following:

- Nearly half of all carers (44%) had experienced a long-term illness or disability themselves within the previous 12 months, compared with 39% in all of NSW

¹ Australian Bureau of Statistics (2016); Australian Bureau of Statistics (2015)

² Based on Primary Health Network Region boundaries

³ Carers NSW (2018), *Carers NSW 2018 Carer Survey: Summary report*, Carers NSW, Sydney

- More than half (51%) of carers had an annual household income of less than \$50,000
- 44% found it “difficult” or “very difficult” to meet their necessary living expenses
- Only approximately 1 in 4 (26%) felt their caring role was recognised by their community
- More than half (54%) reported “high” or “very high” levels of psychological distress, compared to 46% in NSW overall.⁴

Carer health and wellbeing

Carers are known to have consistently lower physical and psychological health and wellbeing compared to their non-caring counterparts.⁵ One Australian study found that carers were more likely to suffer from a chronic condition such as asthma or diabetes, at least one chronic health condition when compared to the rest of the community, and were more likely to report risk factors including high blood pressure and high cholesterol, which can be exacerbated by the caring role.⁶ Similarly, a quarter of all Australian carers experience high or very high levels of psychological distress, and are therefore highly likely to have a moderate to severe mental disorder.⁷ By comparison, around one in ten Australians experience high to very high levels of distress, with the vast majority experiencing low levels of distress.⁸ While not all of this data is publicly available in relation to South-West Sydney specifically, the survey results presented in the last section suggest that these experiences are shared by carers in South-West Sydney.

The determinants of carers’ health and wellbeing are complex and in many circumstances are linked to the stressors of the caring role. In particular, carers with especially time-consuming caring roles, those lacking informal support networks and those who are financially disadvantaged are more likely to have worse health. In areas like South-West Sydney with higher overall levels of socio-economic disadvantage than other parts of NSW, this relationship is particularly important. Further, it is known that carers commonly neglect their own health, putting the needs of the person they care for ahead of their own.⁹ The health implications of providing care continue even after the caring role ends; the emotional distress and physical injuries incurred during the caring role are likely to persist for many years amongst former carers.

Despite the high incidence and known causes of poor health and wellbeing amongst carers, there are currently few services specifically targeted at carers’ own health needs in NSW. Local Health Districts (LHD) carer programs across NSW, including in South Western Sydney LHD, undertake great work in raising awareness of carers and promoting carer participation, however they are not adequately resourced to comprehensively address carers’ physical and emotional needs across the region. NSW Health has a key role to play in setting the course for proactively addressing carers’ physical and mental health needs in order to address ongoing health inequities, as will be explored in more depth in subsequent sections. Primary Health Networks (PHNs) also have a role in ensuring that general practitioners (GPs) are carer-aware and able to refer carers to support services where required. This inquiry provides an excellent opportunity for carers to be more embedded in health service planning within South Western Sydney.

⁴ Ibid.

⁵ Edwards, B., Higgins, D. J., Gray, M., Zmijewski, N., & Kingston, M. (2008) *The nature and impact of caring for family members with a disability in Australia*, Research Report No. 16, Australian Institute of Family Studies, Melbourne.

⁶ Stacey, A., Gill, T. and Price, K. (2017), *A Report Card on Carer Health in SA*, The University of Adelaide, Paper presented at the 7th International Carers Conference, Adelaide, 4th-6th of October 2017.

⁷ Australian Bureau of Statistics (2017)

⁸ Australian Bureau of Statistics (2012), Table 4.1 Level of psychological distress, *Australian Health Survey Australia- First Results 2011-12*, Canberra.

⁹ 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.

Hospital infrastructure

Family and friend carers regularly accompany the person they care for to hospital in both emergency and long stay circumstances. Carers NSW continues to strongly advocate for increased investment in subsidised onsite or local accommodation and parking for carers supporting patients in hospital, especially those travelling from regional and rural areas. It is imperative that these facilities be affordable and accessible, and enable carers to sustainably accompany their family member or friend on visits to hospital and thus contribute to their care.

Accommodation can take the form of purpose-built facilities in close proximity to the hospital itself, especially when longer term stays are required. However, hospital redevelopment also creates the opportunity to develop innovative, cost-effective alternatives for shorter stays within the hospital itself.

For example, as part of the Blacktown and Mt Druitt Hospital expansion, 40 designated Carer Zones have been established within single patient rooms.¹⁰ Carer Zones are a section of patient rooms, containing a curtain and bed and providing privacy and comfort to the carer whilst accompanying the person they are caring for. Due to this innovation, carers no longer have to sleep in a chair and are able to get restful sleep. In addition, carers are also provided with a 'carer card' to access discounted parking.

*Eleanor**s husband Joe* has quadriplegia and was admitted to hospital. There were not enough adequately skilled staff to deal with Joe's high support needs during his hospital stay, so Eleanor had to stay at the hospital to assist with moving and feeding him.*

* Not their real names

Accommodating carers in hospital wards better enables carers to provide ongoing reassurance and emotional support to the person they care for, as well as assist with monitoring the person's condition and completing practical tasks such as feeding and showering. Furthermore, the benefit of subsidised parking recognises the important role of carers and the socio-economic disadvantage that carers often experience as a result of their caring role. Carers NSW recommends that increased investment in accommodation, carer friendly wards and parking subsidies be considered for the South West Sydney growth region to recognise and enable the important role that carers play in the health care of hospital patients.

Health workforce

Carer inclusion in health settings

In the Carers NSW 2018 Carer Survey, carers in the South Western Sydney region reported their experiences of inclusion and recognition across a range of health settings. Nearly 85% reported being included in decision making by the GP of their care recipient, however less than 40% were asked about their needs as a carer when accessing the GP with the person they care for. A lower percentage of carers (76%) felt included in decision making in hospital settings, and less than 30% were asked about their needs as carer by hospital staff. These statistics reflect that many carers are included in decisions about the person they care for, however a large portion remain excluded from their care recipients' health planning, and the majority of carers do not have their needs as a carer considered. Carers NSW strongly

¹⁰ Australian Commission on Safety and Quality in Health Care, (2016) Blacktown and Mount Druitt Hospital support carers, available online at: <http://cognitivecare.gov.au/stories/blacktown-and-mount-druitt-hospital-supports-carers/>

advocates that health services in the South Western Sydney region should promote carer identification, recognition and support to the fullest extent possible.

Education and training

Achieving carer recognition and support in health settings is largely underpinned by adequate education and training of health professionals. This includes educating all staff to ensure familiarity and compliance with the NSW *Carers (Recognition) Act 2010* and the NSW Carers Charter, as well as the NSW Health Recognition and Support for Carers: Key Directions 2018-2020 (the Key Directions). All staff should be sufficiently trained to identify and screen carers, to ensure adequate support and onward referral where necessary. Staff must also understand and incorporate the informal support provided by the carer in their health assessment and planning, and should understand the impact of the caring role on carer health and wellbeing.

Carer health checks

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 Body Mass Index (BMI), blood pressure, cholesterol and blood sugar as well as mental health assessments.¹¹ Evaluation data indicates that health checks led to sustained self-care and healthier behaviours for many carers.¹² Carers reported these checks are an opportunity to attend to their own health needs, and increase awareness of health issues and motivation to follow up with referrals for specialist treatment.¹³ Carers also identified benefits to their psychological wellbeing and recognition of the demands of their caring role.¹⁴

Carers NSW recommends that carer health checks be incorporated within health services in South Western Sydney, whether in public or primary health settings, or both. 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, the 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, particularly through the national Carer Gateway. This includes onward referral to respite services to provide an adequate break from the caring role to sustain carer wellbeing and the caring relationship.

“Carers should also be a priority of primary health care services dealing with people with chronic conditions.”

– National Health and Hospitals Reform Commission (2009)

¹¹ 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.

¹² 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:

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

¹³ Ibid

¹⁴ Ibid.

Conclusion

The sustainability of the health care system across NSW and in South Western Sydney depends on the contribution of unpaid carers, who are the major providers of health care in the community.¹⁵ This dependence is even higher in diverse communities with lower socio-economic status, such as parts of South-West Sydney. Across NSW, carer programs are doing important work within the Local Health Districts (LHDs) to create health systems which are more responsive to the needs of carers. Within and outside of this context, carers of people using health services in South Western Sydney should be recognised, included and supported to navigate the system for their care recipients, and access the health system for themselves.

¹⁵ National Health and Hospital Reform Commission (2009) *A healthier Future for all Australians – Final report of the National Health and Hospitals Reform Commission*, Australian Government, Canberra.