9 February 2015

Amanda Larkin
Chief Executive
South Western Sydney Local Health District
c/o gay.horsburgh@sswahs.nsw.gov.au

Dear Ms Larkin

Re: Development of a Palliative Care Strategic Plan for South Western Sydney

Carers NSW supports and advocates for all carers of a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail in NSW. Carers NSW believes the Strategic Plan has the potential to greatly improve support for carers of people requiring palliative care in SWSLHD and we thank you for the invitation to be involved. Carers NSW would like to note that as our focus is on state-wide advocacy, we do not necessarily have the local knowledge needed to provide specific regional advice.

What are the gaps, needs and concerns of carers of people in south western Sydney with palliative care needs when attending local general practitioners, hospitals, community health services or residential aged care?

Carers NSW has limited knowledge of issues specifically faced by carers in SWSLHD, and we are unable to provide locally specific information in this response. However, we have heard from carers across NSW who share a number of concerns in regards to their experience with health services, including:

Lack of recognition and inclusion

Carers and family members often report feeling invisible in the health system, and they report that they do not receive adequate information about the patient they care for, nor do they receive information about support available to them as carers. Carers also report that health professionals do not respect their expertise or consult them in decision-making.

It is evident to Carers NSW that despite the introduction of the carer policies and legislation at the state and territory level, carers are still not systematically included as partners in care within the health system. Although there are some commendable instances of carer inclusion occurring, these are often limited to particular programs, hospital sites or service providers, and are not indicative of the general situation for carers within the health system.
Including carers as partners in care can benefit the carer, the care recipient and the health service provider, and can lead to improved information and feedback, increased compliance and improved quality of care for the care recipient.

**Difficulty in addressing carers own health needs**

It is well established that carers are more likely than non-carers to experience reduced physical, mental and emotional health, and many carers are unlikely to seek help for their own health needs as they are so focused on the health of the person for whom they are caring. Carers NSW advocates for the health sector to recognise carers reduced health and wellbeing as an unacceptable inequity, and to seek to actively address this inequity.

Carers NSW asserts that the health and wellbeing of carers could be significantly improved if providers routinely identified and supported carers to undertake their caring role, and assisted carers to access the health services and support that they need. These health services must be accessible to carers, considering carers often limited time, energy and resources.

**Fragmentation of the health system**

Carers report that health services and practitioners involved in supporting the patient may not communicate with each other or work together. Lack of communication and disconnection in health care provision is particularly challenging for carers who are navigating the health system in addition to other service structures, including aged care and disability services. We often hear from carers who are lost in a service maze and are overwhelmed by the different service providers who are involved in their loved one’s care. It is these family members who are left to take on the role of care coordinators and advocates for their loved ones, and they often communicate information between health professionals who do not communicate with each other.¹

In-depth research by Alzheimer’s Australia has highlighted the experiences of people with dementia and their carers interacting with the health system and community based services.² They found services to assist the person with dementia and their carer during the transition from hospital to home were complex and difficult to navigate, and noted that a ‘better, person-centred, transition process from hospital to home is urgently required’.³ Alzheimer’s Australia emphasised the need for consultation between health professionals, carers and community-based services in order to help carers navigate the service options available to them.

There are also significant challenges for people with a disability and their carer in interactions with the health system. National Disability Services report *Creating Inclusive NSW Hospitals*, released in July this year, drew attention to these challenges and called for NSW Health to employ specialist workers trained to coordinate the support of people with disability in hospital.⁴ Carers NSW believes these workers would be well placed to manage interactions between the hospital, people with disability, their families and carers, mainstream health and disability support systems.

In consideration of these challenges, Carers NSW is a strong advocate for integrated care, which aims to improve the quality of care for consumers and carers by ensuring services are well-coordinated around their needs. An integrated health care system needs to provide continuity of care not only within the health system, but also more broadly.

Carers NSW is particularly keen to see initiatives which support inter-sectoral integration advanced in NSW, and NSW Health’s *Integrated Care Strategy 2014-2017* has committed NSW to innovative models of integrated care.
Analysis in the 2014 Bureau of Health Information report ‘Patient perspectives – Exploring aspects of integration for hospital patients’ revealed relatively poorer results for SWSLHD in areas such as responsiveness to patients’ needs and expectations, involvement of patients in decisions and consideration of family and home situation when planning discharge. These results indicate that delivery of integrated care should be a priority for SWSLHD.

Carers NSW anticipates that in the development of the Palliative Care Strategy, SWSLHD will consider alignments with the Integrated Care Strategy, and explore opportunities to advance integrated care.

Cost of healthcare

The cost of healthcare, including specialist fees, can particularly deter carers from addressing their own health needs. Almost two thirds of primary carers live in low income households, that is, a household with equivalised gross household income in the lowest two quintiles, compared with 36 per cent of non-carers. Carers NSW regularly hears from carers who place the health needs of the person they care for ahead of their own, and can neglect their own health in the process.

The Griffith Health Institute recently found that people with chronic illness and their carers in Australia thought that the financial cost of treatment—particularly the cost of medication and consultations with healthcare professionals—was the most concerning aspect of treatment burden.

Diverse carer groups

There are also additional challenges for carers from particular groups that are often marginalised, including:

- Carers from Aboriginal communities due to differences in cultural beliefs and understanding of values such as family and care, and often past experiences of discrimination and trauma in institutions
- Carers from culturally and linguistically diverse backgrounds who may have, or may be caring for someone who has, differences in language, cultural beliefs and practices
- Young carers (i.e. children and young people up to the age of 25) who are less likely to be recognised as carers, but who are likely to find caring for a family member particularly challenging due to their age and relative inexperience (especially if they are the primary carer)
- Lesbian, gay, bisexual, transgender or intersex (LGBTI) carers, who often face multiple invisibilities and lack of recognition of their identity, their relationships and/or their caring role. LGBTI carers also face many challenges to their mental and physical health and wellbeing.

Is your agency intending to implement any new initiatives in the next three-five years which may directly or indirectly benefit or support the carers of people with palliative care needs?

Carers NSW is closely involved in the implementation of the NSW Carers Strategy 2014-2019. While there are no projects directly focussed on carers of people with palliative care needs, the Strategy includes projects which aim to:

- Improve the design and delivery of services and programs in ways that make it easier for carers to look after their own health and wellbeing,
- Embed and improve information for carers in the trusted systems they frequently use, and
• Continue to improve the ways we involve carers as partners in the care delivered to their loved ones.

The implementation of the NSW Carers Strategy should benefit all carers in this state, including carers of people requiring palliative care and carers in South Western Sydney.

Carers NSW is also working with the Department of Social Services (DSS), through the Network of Carers Associations, to identify an Integrated Carer Support model. Carers NSW is advocating for the new model to support all carers, including those caring for a person with palliative care needs, regardless of their age or particular condition. Unfortunately, this discussion has been ongoing for several years and there is uncertainty regarding not only when and how this will be implemented, but also continuation of funding for existing programs which support carers in the meantime.

What do you think that SWSLHD should do to improve the support provided to carers of these residents? What opportunities are there to work with you?

In addition to actions recommended previously, Carers NSW suggests that SWSLHD:

• Engage with Carers NSW Carer Representation Program, which trains carers to become Carer Representatives to share their insights and experience through participation in committees, consultations, guest speaking and other activities.

• Engage with Carers NSW free training and education which targets different groups including:
  o Organisations who wish to build the capacity of their staff who work with carers,
  o Carer and community groups about topics such as self-care and taking a break, and
  o Training for facilitators of carer support groups.

• Participate in the Carers NSW Biennial Conference (21-22 May 2015) with the theme ‘Let’s revolutionise caring: inclusion, innovation, diversity’.

• Raise awareness of services available to carers, including Carers NSW Carer Line, National Carer Counselling Program and the Young Carer Program.

Thank you again for your interest in supporting carers and the invitation to be involved in this process. If you would like further information regarding this submission please contact Louise Bradley on (02) 9280 4744 or by emailing lousieb@carersnsw.org.au. For further information about Carers NSW programs, or to request resources or training, please contact the Carer Line on 1800 242 636.

We look forward to working with you further.

Yours sincerely,

Elena Katrakis
CEO
Endnotes

3 Ibid, p. 7.
4 NDS (2014). Creating Inclusive Hospitals in NSW.