CCNSW submission to NSW Government Palliative Care Roundtables consultation

December 2017 (Online submission)

Providing flexible access to care through a range of strategies

Flexible access to support 24 hours a day, 7 days a week is an important element of palliative care, especially when care is being provided at home or a residential aged care facility. 24 hour access to specialist palliative care, for those who need it, is even more critical. Specialist care may be needed quickly for the control of, for example, acute pain or other symptoms or when the carer or family are in acute distress. While the strategies suggested in the consultation paper may be appropriate for some levels of palliative care, further consideration may be required to establish which ones ensure that specialist palliative care can be provided quickly and efficiently wherever someone lives in NSW. This includes how someone in need can be assessed, and cared for, in person by a specialist palliative care doctor, nurse or allied health professional when needed.

The action that could be taken to deliver on this theme is to ensure each local health district has enough specialist palliative care professionals to be available for people who need specialist care when and where they need it.

Care is centred on the patient

Cancer Council agrees that there should be integrated and coordinated palliative care services that patients, their families and carers can easily navigate. Specialist services are a critical part of palliative care so they also need to be integrated and coordinated and easy for patients and their carers to access and navigate. Currently this is not the case for everyone who needs specialist palliative and end-of-life care, particularly in rural and regional local health districts (LHDs) where there are access gaps and existing services may be limited and over-stretched. Each LHD needs to ensure that there are enough specialist staff to plan and implement an integrated and coordinated specialist service and to participate in developing local policies to ensure easy access to that service.

Aboriginal people who are already disadvantaged because they are more likely than non-Aboriginal people to live in rural and regional NSW, are further disadvantaged. This relates to the difficulty of navigating palliative care services that are unlikely to fit with community values, beliefs, cultural/spiritual rituals, heritage and place.

The action that could be taken to deliver on this theme is to include in the Government's new palliative and end of life care policy framework a requirement that LHDs have enough specialist palliative care doctors, nurses and allied health professionals, based on local population demographics; and that specialist staff are involved in planning and implementing a specialist service that is integrated and coordinated with other health services in the LHD, and in developing local policies to ensure easy access to that service.

Develop a model of care for culturally appropriate palliative and end-of-life services for Aboriginal people. Aboriginal people need to be involved in decision-making about developing and implementing such a model, and the cultural needs of locally-based communities, including families, kinships and tribes, must be considered. Training and scholarships may provide an opportunity to progress culturally appropriate services. One option may be to allocate a proportion of the 2017 state budget scholarship money to train Aboriginal staff to become specialist palliative care doctors, nurses and allied health professionals. In addition, ensure that on-the-job training in palliative care for non-Aboriginal nurses and allied health staff includes education about the cultural needs of Aboriginal people living with an advanced or terminal illness.

A skilled and supported workforce

Currently, more specialist palliative care services are needed in rural and regional local health districts (LHDs) where some people in need are still relying on general practitioners and generalist community nurses for palliative care, especially after-hours. Cancer Council acknowledges that the NSW Government's recent funding for 9 additional palliative specialists, two relief specialists and two additional palliative care nurses per LHD, in rural and regional areas will address some of these needs.

However it is critical that every regional and rural LHD has the right number of specialist doctors, nurses and allied health professionals to ensure the provision of around-the-clock specialist services to people who need it, where they need it, within their own local LHD. Enhancing the specialist workforce may occur by providing meaningful opportunities for LHD staff to become specialist in their field and move into designated positions, as well as incentivised opportunities for trained staff from interstate and overseas.

This will also ensure that within each LHD, GPs and other staff such as oncologists and geriatricians, general community health nurses, allied health staff, pharmacists, care workers and volunteers will be able to access expert information and support to ensure optimum care for the patient and their carer.

The action that could be taken to deliver on this theme is to include in the Government's new palliative and end of life care policy framework a requirement that LHDs have a workforce plan for specialist palliative care doctors, nurses and allied health professionals that is based on local population demographics and need; and that the LHDs report against key performance indicators for these annually. Where there are shortfalls unallocated money from the Government's commitment of $100 million could be used for specialist palliative care staff.

Providing suitable spaces for care

Cancer Council agrees that everyone should have access to palliative care when they need it, no matter where the care is provided. As mentioned in the consultation paper, access to equipment where needed, home-like facilities and improved facilities for carers and families is important, as are dedicated palliative care rooms in locations such as residential aged care facilities. However local health districts (LHD) also need to have fully staffed, integrated palliative care services, according to population demographics, so that anyone requiring

palliative or end-of-life care doesn’t have to move out of their LHD to receive care. The service needs to ensure that they can provide care wherever someone needs it, including in a specialist palliative care inpatient bed if required.

The action that could be taken to deliver on this theme is to include in the Government’s new palliative and end of life care policy framework, how LHDs will ensure they have fully staffed, integrated palliative care services, which provide care wherever needed. For example, this may be the person’s home, a residential aged care facility or palliative care unit, but it also needs to include specialist palliative inpatient beds.