

FREQUENTLY ASKED QUESTIONS: More Specialist Palliative Care

Q: Why is Cancer Council NSW recommending funding for a minimum of an additional 10 palliative physicians?

A: The most recent published data from the Australian Institute of Health and Welfare shows that, in 2014, NSW had the equivalent of 67 full time palliative physicians working across the state. This is fewer than the ratio recommended by the Australian and New Zealand Society of Palliative Medicine. Based on their recommendation NSW needs the equivalent of 77 full time palliative physicians for the current population – or 10 more.

Information recently provided by local health districts to Dr Yvonne McMaster, of Push for Palliative suggests that, as of October 2016, there are 63.2 full time physicians funded for NSW, which is less than the 67 outlined in the workforce data from 2014. This reinforces that NSW needs, at a minimum, funding for 10 more palliative physicians.

Q: The Minister says that NSW already has more than 77 palliative physicians so doesn't that mean the problem is solved?

A: No the problem is not solved. The Minister is referring to different data which is the number of physicians that have undertaken specialist palliative physician training and are fellows of palliative medicine within the Royal Australian College of Physicians. However someone may be a fellow of palliative medicine without currently working as a palliative physician. Therefore the data used by the Minister doesn't give an accurate picture of palliative physician services being provided on the ground. The most reliable, systematically collected, public data is the yearly national workforce data where medical professionals note their main area of work and how many hours a week they work there.

Q: Why is Cancer Council NSW recommending funding for an additional 129 palliative care nurses?

A: The most recent published data from the Australian Institute of Health and Welfare shows that, in 2014, NSW had 813 full time palliative care nurses working across the state. This was the same rate of nurses per head of population as the previous year. It also showed that NSW has the lowest number of palliative care nurses per population of any Australian state or territory. Presuming that the NSW Government's 2013 funding promise for palliative care nurses/nurse practitioners positions has been fulfilled we still need another 129 full time palliative care nurses to fill the shortage across the state and bring us up to the standard of the rest of Australia.

Q: Is it fair to ask for more when there has been significant funding for palliative care in NSW over the past few years?

A: Yes, while the NSW Government has provided funding for a number of palliative care initiatives, outlined below, access to *specialist* palliative care is still a problem across the state. Currently the number of palliative physicians in NSW still falls short of the 1.0 FTE per 100,000 population needed and there is approximately 129 less palliative care nurses than needed across the state. The Government notes the importance, and lack of access to, specialist palliative care in a range of its policy documents including *the NSW Government Plan to increase access to palliative care 2012-2016*, and the Agency for Clinical Innovation's *Framework for the statewide model for palliative and end of life care service provision* and *Palliative Care – a blueprint for improvement*.

Government initiatives since 2012 include home care packages, support for volunteer services and a palliative care after-hours telephone support service. The government has also funded seven positions for palliative physician training and an additional 30 palliative care nurses and an extra four nurse practitioners. Despite this workforce funding the latest figures show that we still have 10 fewer palliative physicians than recommended by the Australian and New Zealand Society of Palliative Medicine, and information provided by local health districts to Dr Yvonne McMaster, of Push for Palliative, suggests that the gap may be higher. We also have the lowest number of palliative care nurses per population of any Australian state or territory. We need an extra 129 FTE palliative care nurses to fill the shortage, particularly in regional, rural and remote NSW.

Q: How many funded positions are there in each local health district and are they all filled?

A: Published data about the number of funded positions is only available on a statewide basis rather than per local health district, and vacancies are not publicly reported. Information recently provided by local health districts to Dr Yvonne McMaster, of Push for Palliative, suggests that as of October 2016 there is funding for 63.2 full time physicians across NSW, with some positions being vacant.

Based on the published data, Cancer Council NSW is recommending funding for the equivalent of an additional 10 full time palliative physicians at a minimum, and an additional 129 full time palliative care nurses. Funding for these would be allocated to the local health districts based on the greatest need, which is likely to be in regional, rural and remote NSW.

Q: If the NSW Government provides the funding for more positions, do we have enough palliative physicians and palliative care nurses to fill them?

A: This information is not available to Cancer Council NSW. However, since 2012, there has been an improvement in the ratio of palliative physicians per capita which may have been the result of the NSW Government's recruitment and retention strategies. Similar strategies could be used to achieve our recommended increases.

Q: In March 2015 the NSW Government made an election promise that, if re-elected, they would fund 700 more doctors and 2,100 more nurses over the next four years. Can these positions be used for specialist palliative care?

A: This would be one way to increase the specialist palliative care workforce in NSW, providing that those employed have the knowledge, skills and experience needed to provide specialist palliative care, or are supported by their employer to develop them. However it is still unclear where, or when, these extra positions will be allocated.

Q: Is there a problem with the quality of palliative care available now?

A: No, feedback from patients and their families who have accessed a specialist palliative care team is positive. However there just isn't enough of it. This means that not everyone with a life-limiting cancer who needs specialist palliative care has access to it, when they need it, wherever in NSW they live.

Q: Isn't it enough that there are general practitioners (GPs) who are interested in palliative care and are providing a good service?

A: In addition to the care provided by their own GP, a person with a life-limiting cancer deserves to have access to a specialist palliative care team, when they need it, wherever in NSW they live.

A GP may be an important member of the team providing primary care that is needed throughout a patient's journey, including during the palliative and end of life stages. However, GPs aren't trained as palliative physicians. General practice is a specialty of its own that is different from the speciality of palliative medicine, and their postgraduate qualifications differ. Therefore GPs can't provide the level of specialist skill, knowledge and experience offered by a palliative physician. Our recommendation is specifically focused on increasing specialist palliative care across NSW.

Q: What is the NSW Government saying about specialist palliative care services?

A: The *NSW Government plan to increase access to palliative care 2012-2016* says that access to specialist palliative care is not uniform across the state and that one of the reasons why more people do not get to die at home is that specialist palliative care services are limited in rural and remote areas. The Agency for Clinical Innovation's *Palliative Care – a blueprint for improvement*, which is a guide for local health districts, emphasises that when patients have complex needs, access to specialist palliative care is essential.

Q: What role would palliative physicians and palliative care nurses have in an acute care hospital?

A: Palliative physicians and palliative care nurses have specialist knowledge, skills and experience that can be provided in any setting, including in an acute care hospital. They may receive referrals from anywhere in the hospital such as a neonatal unit or a children's ward, the intensive care unit, a general ward or a geriatric ward. They may provide all the care to the patient in a designated palliative care unit within the hospital or they may provide a consultancy service to other teams in the hospital, supporting them to treat pain and other complex problems, and to reduce unnecessary or overly intrusive medical interventions. Also, they help plan care and teach hospital medical, nursing and allied health staff.

Q: What role would palliative physicians and palliative care nurses have outside of an acute care hospital?

A: A specialist palliative care team should be able to provide care to a patient wherever they are, which may include at a community-based service, in their home, residential aged care facility, prison or psychiatric facility. Their specialist role is the same wherever they provide their care.

Q: Is this going to encourage euthanasia or assisted suicide?

A: No, specialist palliative care is not the same as euthanasia or assisted suicide, and palliative physicians and palliative care nurses know that both are illegal in Australia. Palliative physicians and palliative care nurses don't try to end life sooner, instead, they use their specialist knowledge, skills and experience to maintain the patient's comfort and quality of life throughout the stages of a life-limiting cancer. Some studies show that controlling symptoms, such as pain, can lead to people living longer than expected.

Q: Would getting the extra positions make it any better for people who are too sick to die at home, or those who make a choice to go to a palliative care unit or hospital?

A: Yes, more palliative physicians and palliative care nurses will allow those patients who are too sick to die at home, or who choose to be moved, to have continuity of specialist palliative care wherever they are in NSW. Unfortunately, it is not possible for many palliative care teams to offer this level of service as they don't have enough staff.

Q: The Minister for Health says that staffing is the responsibility of local health districts. So why not focus the advocacy on local health districts instead?

A: While local health districts are responsible for staffing of specialist palliative care services, more designated funding from the NSW Government will allow them to fulfil their staffing needs.

Q: How do PC volunteers fit in?

A: Palliative care volunteers play an important role and the NSW Government has provided funding of one million dollars over four years to support their work. Most are attached to, or have a close working relationship with, a specialist palliative care service. While volunteers make it possible for some people to fulfil their wish to die at home, they do not improve access to specialist palliative care.

Q: What does culturally appropriate palliative care services for Aboriginal people mean?

A: More work is needed in this area and it needs to be guided by established principles, including that palliative care services are more likely to be effective when Aboriginal people are integrally involved in their development and implementation. Principles ensuring that services are culturally appropriate to the particular needs of individuals and groups, that includes families, kinships and tribes, also need to be emphasised. This includes being mindful of spoken and unspoken communication styles and language, and the need to allow Aboriginal people to take care of business and undertake cultural practices and rituals related to end of life and finishing up/dying.

Q: What will CCNSW's recommendations cost and where will the money come from?

A: This will depend on the number of specialist palliative care staff needed. There are specified pay rates for medical specialists, and for nursing staff, in the public sector. This means that the cost of 10 palliative physicians, at a minimum, and 129 palliative care nurses may be easily calculated. When the NSW Government is clear about how much it will cost to develop culturally-appropriate specialist palliative care services for Aboriginal people, they will be able to calculate the overall cost. Decisions about where the money comes from are made by the Ministry of Health in collaboration with the NSW Treasury.