

BRIEFING PAPER: More Specialist Palliative Care

Goal

Ensure that every person with a life-limiting cancer who needs specialist palliative care has access to it, when they need it, wherever in NSW they live.

Background

Specialist palliative care is an approach that improves the quality of life of patients and their families who are experiencing problems associated with a life-limiting illness. It prevents and relieves suffering through early identification; and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Specialist palliative care can be offered early in the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.¹

The specialist palliative care team, which includes palliative physicians, palliative care nurses and allied health staff, can provide care in a variety of settings. Examples include acute hospitals, palliative care inpatient units, community-based services and a person's home, which may be a residential aged care facility. To become a palliative physician, a doctor must complete a formal qualification in palliative medicine and be admitted to the relevant college. Palliative care nurses will, in general, have a formal qualification in palliative care nursing or the experience to provide the care needed. The specialist palliative care team works closely with other health professionals involved including general practitioners (GPs) and other medical specialists, such as oncologists or geriatricians. The team also collaborates with generalist community health nurses and allied health staff, community pharmacists, care workers and volunteers who provide care.

Policy context

The NSW Government plan to increase access to palliative care 2012-2016 acknowledges that there are gaps in specialist services, especially in rural areas. It also recognises that culturally appropriate palliative care services for Aboriginal people are lacking.² Other significant policy documents from the NSW Government's Agency for Clinical Innovation's (ACI) Clinical Network for Palliative Care include: *Diagnostic Report to inform the model for palliative and end of life care service provision*; *Framework for the Statewide Model for Palliative and End of Life Care Service Provision*; and *Palliative and End of Life Care - a blueprint for improvement*. All have identified gaps in specialist services for end-of-life care in NSW.³⁻⁵

Since 2012, the NSW Government has funded several initiatives including the *Last-days-of-life home support service* which provides up to 48 hours of home-based support at the end of a person's life. It is provided by contracted non-government organisations, such as Silver Chain and HammondCare. The service is available within every local health district (LHD), however access across the whole geographical area of the LHD may not be guaranteed. Also, funding of one million dollars over four years has been provided to support palliative care volunteers. While these initiatives make it possible for some people to fulfil their wish to die at home, they do not improve access to specialist palliative care. Recently, the NSW Government funded the Palliative Care After Hours Helpline which is operated by Healthdirect Australia. The Helpline is staffed by Registered Nurses, who can refer to a specialist palliative care nurse when callers with more complex issues require advice and support.

Since 2012 the NSW Government has also provided funding for an extra 30 palliative care nurse and four palliative care nurse practitioner positions,⁶ and seven palliative physician training positions.⁷

In 2015, the Minister for Health also announced a Flexible Funding Pool of \$12 million over four years, to help LHDs identify their specific needs and develop models of care to enhance access to palliative care. This equates to approximately \$3 million per year divided between fifteen LHDs. The small amount of funding each year, and the limited timeframe, make it unlikely that it will be used to increase the number of palliative physicians or palliative care nurses.

A spokesperson for the Minister for Health announced that the state government had committed to funding an additional 60 medical training positions in specialities including palliative care during the next four years. However it is not clear how many of these training positions will be allocated to palliative physician training.⁷

The NSW Government has also developed the *Advance Planning for Quality Care at End of Life: Action Plan 2013-2018* which seeks to improve end of life care by integrating patients' wishes into the management of chronic life-limiting illness.⁸ However, without appropriate access to specialist palliative care services, the ability to honour and integrate patients' wishes for their end-of-life care may be limited.

Problem

Some people with a life-limiting cancer who need specialist palliative care, near where they live, won't be able to get it. As a result, they'll be denied the best quality of the life and their wishes documented in an Advance Care Plan may go unfulfilled. There's also a risk that they won't die in the place of their choice, which for approximately 70% of Australians is at home.² It's estimated that more than three-quarters of all people who die in NSW could benefit from specialist palliative or end-of-life care.³ As there are 14,000 cancer deaths yearly in NSW, a figure that is projected to rise, the need for specialist palliative care for people with a life-limiting cancer in NSW will increase for the foreseeable future.⁹

People in their last year of life get admitted to acute hospitals more often and stay longer, and have a higher proportion of unplanned emergency visits, resulting in a poorer quality end-of-life care.^{3;10-16} In these situations, painful procedures and treatments of little or no use may be avoided if a specialist palliative care team is involved. Also the family and carer/s, who may experience extensive demands that compromise their own health, won't get the care they need if there is no specialist palliative care team available.

Regional, rural and remote communities experience gaps in access to specialist palliative care, particularly in remote areas where most types of services are limited and over-stretched.³ Aboriginal people, already disadvantaged because they are more likely than non-Aboriginal people to live in these areas, are further disadvantaged by their limited access to specialist palliative care that fits with their community values, beliefs, cultural/spiritual rituals, heritage and place.¹⁷

The current model of service suggests that specialist palliative care services located in large regional centres provide outreach to smaller regional centres, who in turn are responsible for services to smaller towns within a large radius. However information provided by LHDs to Yvonne McMaster, of the Push for Palliative campaign, indicates that there are a number of large regional centres where access to palliative physicians is not available. In other areas specialist palliative care may consist of one solo, part-time palliative care nurse with responsibilities across a large area, who may, or may not, have access to a palliative physician remotely.^{18;19} Support often depends upon the goodwill and commitment of palliative care staff who live and work in regional and rural communities. The lack of local access may mean that a person and their family have to travel for specialist palliative care, creating practical, emotional and financial problems,² or it may mean going to an emergency department or doing without. Provision of specialist palliative care after hours is unsatisfactory in rural and remote NSW.

The government highlights that people should have access to a specialist consultation and direct care if their care needs exceed what can be accessed from primary care providers. Known as level one specialist palliative care, this should be available locally as a minimum for all patients approaching and reaching the end of their life.⁴ However, this is still a gap and the government has indicated that it needs to be addressed.⁴

In NSW, the number of palliative physicians is less than we need. The most recent workforce figures show that, in 2014, NSW had 0.9 full time equivalent (FTE) palliative physicians per 100,000 population.²⁰ This is less than that recommended by the Australian and New Zealand Society of Palliative Medicine (ANZSPM) which is 1.0 FTE palliative physicians per 100,000 population as a minimum for an adequate specialist palliative care service.²¹ Palliative Care Australia recommends a higher rate of 1.5 FTE per 100,000 population to ensure the ongoing development of the specialty.²²

Also, there is a significant shortage of palliative care nurses. The most recent workforce figures show that, in 2014, NSW had a rate of 10.8 FTE palliative care nurses per 100,000 population which was the lowest rate in Australia.²⁰ This put NSW below the 12.47 FTE per 100,000 population for the other states and territories combined.²⁰ This meant that, in 2014, NSW was in deficit by 1.67 FTE per 100,000 population.

While other medical specialists and primary health care providers also have important roles to play they are not trained to provide specialist palliative care and rely on access to specialist palliative care teams for support. The gaps in the specialist palliative care workforce limits the specialised knowledge and support available to the range of service providers involved.³

Solution

All cancer patients, and their families, need access to the level and type of palliative and end-of-life care required to address their needs within a reasonable distance to where they live.⁵ When we have more palliative physicians and palliative care nurses, there will be more specialist palliative care services. This means it will be available in acute hospitals, palliative care units and community based services, including in a person's home or residential aged care facility, regardless of where that is located in NSW. It will also mean more time for the specialist palliative care team to collaborate with other medical specialists and primary care providers, and provide them with more support and education as required.

Cancer patients who have access to specialist palliative care are more likely to have an improved quality of life including significantly better control of pain, symptoms and anxiety. They also experience fewer medical interventions, emergency department visits or hospital admissions at the end of their life and are less likely to die in hospital, resulting in significant cost-savings to the health system.^{3;10-16;23} Access to specialist palliative care can also help to reduce carer/family stress and burden, which is often a barrier to those who want to die at home being able to do so.^{24;25} In addition, provision of bereavement care and preparatory grief work by the specialist palliative care team may help prevent medical problems for carers and family members at risk of developing complicated or prolonged grief.^{11;12;26} Overall, specialist palliative care improves clinical outcomes, patient-centred decision-making and care coordination, and reduces hospital costs through significant reductions in pharmaceutical, laboratory and intensive care unit costs.^{11;12;27}

Based on the ANZSPM's recommendation of 1.0 FTE palliative physician per 100,000 population, NSW needs 77 FTE palliative physicians to service our current population of approximately 7.7 million.²⁸ Assuming that no more palliative physicians have joined the workforce since 2014 when there were 67 FTE palliative physicians working in NSW,²⁰ an extra 10 FTE palliative physicians are needed. Information recently provided by LHDs to Dr Yvonne McMaster, of Push for Palliative, suggests that, as of October 2016, there were 63.2 full time physicians funded for NSW, which is less than the 67 outlined in the workforce data from 2014.¹⁹ This reinforces that NSW needs, at a minimum, funding for 10 more palliative physicians.

There are no recommended ratios about palliative care nurses, however a comparison to other parts of the country is useful. In 2014 there were 813 FTE palliative care nurses working in NSW, or 10.8 FTE per 100,000 population.²⁰ This was 1.67 FTE per 100,000 population less than the other states and territories combined.

Applying the same deficit of 1.67 FTE per 100,000 population to our 2016 population, and presuming that all funding commitments since 2012 have been implemented and that there had been no change in the workforce since 2014, NSW needs an extra 129 FTE palliative care nurses to bring us up to the standard of the rest of Australia.

The development of a model of culturally-appropriate specialist palliative care for Aboriginal people in NSW 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.²⁹ 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.^{30;31} 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.³¹

Actions

Cancer Council NSW recommends that the NSW Government provide additional funding for:

- 10 FTE palliative physicians, at a minimum
- 129 FTE palliative care nurses
- culturally-appropriate specialist palliative care services for Aboriginal people.

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