



Queensland Nurses' Union

Inquiry into palliative care services and home and community care services in Queensland

Submission to the Health and
Community Services Committee

August, 2012



Introduction

The Queensland Nurses' Union (QNU) thanks the Health and Community Services Committee (the Committee) for providing the opportunity to comment on palliative care and home and community care services in Queensland. In this submission we comment on the capacity and future need for these services, their effectiveness and opportunities for reform. The QNU believes that improving palliative care services is good public policy because it can reduce pressure on the acute sector and distress on the patient and carer(s). Nurses play a significant role in this area.

Nurses and midwives¹ are the largest occupational group in Queensland Health and one of the largest across the Queensland government. The QNU - the union for nurses and midwives - is the principal health union in Queensland. The QNU covers all categories of workers that make up the nursing and midwifery workforce in Queensland including registered nurses, registered midwives, enrolled nurses and assistants in nursing who are employed in the public, private and not-for-profit health sectors including aged care.

Our more than 49,000 financial members work across a variety of settings from single person operations to large health and non-health institutions, and in a full range of classifications from entry level trainees to senior management. The vast majority of nurses in Queensland are members of the QNU.

Palliative Care Nursing

Registered and Enrolled nurses, general practitioners and other specialist or generalist groups play a vital role as providers of palliative care in acute settings, hospices, aged care facilities and in the home. In particular, registered nurses take on the care co-ordination and liaison role for people undergoing complex treatment and care across multiple services and specialities. They are intimately acquainted with the difficulties faced by people due to distance from nearest available health care services, those living in poverty, the homeless, or otherwise marginalised from mainstream health care services.

Palliative care nurses have extensive knowledge and experience in the management of pain and complex symptoms associated with terminal illness. They work collectively and with other professional groups to advance the body of knowledge about end of life care, initiating and conducting research and incorporating research findings into their practice where appropriate. They work collaboratively with others to advocate for change and provide policy advice to government and professional organisations regarding a wide range of clinical, professional and service related issues (Palliative Care Nurses Australia Inc, 2012).

The QNU believes that people with a terminal illness have the right to a choice, both in the care and treatment which is provided to them and in the way in which that care and treatment is provided.

¹ The terms 'nurse' and 'nursing' include 'midwife' and 'midwifery'.

The care and treatment of the person with a terminal illness must be consistent with the person's beliefs and cultural expectations. People with a terminal illness have the right to access specialist palliative care services. These include controlling pain, relieving other symptoms of disease and providing emotional and psychosocial support in preparation for death (Australian Nursing Federation, 2012).

The capacity and future needs of these services (including children and adolescent's palliative care).

The QNU considers that the effectiveness of palliative care services relies heavily on early referral for optimal outcomes. Palliative care must be adequately resourced and supported. This requires an exploration of service demand now and in the future, and how and where this demand can be best met. This should occur in discussion and collaboration with consumers, their families and health care professionals.

Queensland needs an appropriate planning model to address the ageing population and the rural and remote settings. We believe that existing service gaps must be addressed to meet the demands of the future. This will require, for example, ensuring there is a move to models of care that provide palliative care in existing services (that is, acute and aged care settings). Specialist palliative care services must be better resourced (funding and personnel) and available to enable in-reach response where such models are not possible and/or comprehensive, that is, an integrated model (Australian Nursing Federation, 2012).

The availability of a parent or significant other to support the provision of care and to support the child or adolescent requiring palliative care services is paramount. Parents and families should be supported to keep children and adolescents at home for palliative and end of life care wherever possible. Being in their own environment with their family, friends and pets nearby, reduces the stresses associated with palliation and facilitates dying with dignity. Links between nursing and medical services must be optimised, to foster trust, support and respect for the person, family and the health professionals involved in the provision of such care (Australian Nursing Federation, 2012).

It is the view of the QNU that paediatric and adolescent palliative care services should strengthen their links with regional, rural and remote communities to support children/adolescents to remain in their local community. Where it is not possible for children and younger adolescents to remain at home, they should be cared for in a dedicated paediatric hospice.

We consider that it is not appropriate for children/adolescents to be cared for in an adult hospice environment.

The effectiveness, efficiency and adequacy of palliative, frail and chronic care services

Palliative care is enhanced through a multidisciplinary approach that brings, nursing, medical, and allied health care professionals across primary care and clinical specialties, and including psychological and social support and care. Open communication between all health care professionals and integration of care approaches provide greater clarity and consistency for the individual and his/her family/carers. There is some limitation to this model, particularly in rural and remote areas where a nurse may be the sole health professional who is physically present.

In the acute hospital setting, services such as the Hospital in the Nursing Home team at Royal Brisbane and Women's Hospital work to prevent inappropriate admissions of aged care facility residents to the acute setting. Such programs reduce stress for patients/residents and families, prevent inappropriate use of scarce funding and resources, and help ensure a dignified death at home rather than in an Emergency Department.

The Palliative Care Nurse Practitioner role is a key element in the provision of expert palliative care across metropolitan, rural and remote settings. Palliative Care Nurse Practitioners work autonomously, provide professional leadership, use their expert clinical knowledge, extensive experience and advanced clinical skills to ensure that care is coordinated and responsive to the individual requiring the care, their family/friends, and the community. We believe that there is scope to increase the number of Nurse Practitioners in palliative care.

Opportunities for reforms to improve collaboration and co-operation between chronic, disability and other health services.

People with a disability have a long-term physical, mental, intellectual or sensory impairment. An increase in the life expectancy for people with an intellectual disability has resulted in many living into an old age with diseases such as cancer and dementia. Many people with an intellectual disability live at home with their elderly parents who may have a serious illness (Tuffrey-Wijne, 2003).

The support of people with disabilities is important throughout their life. End of life care for people with disabilities needs to encapsulate all the principles of good palliative care. Special focus on physical comfort, symptom control, pain assessment, cultural, psychological, social, spiritual needs and appropriate care management, are essential to quality care. Grief and bereavement support to family, friends and carers should reflect their level of commitment throughout the disabled person's life (Tuffrey-Wijne, et al. 2008).

The QNU considers that people with a disability are under-served in relation to palliative care and this shortfall needs to be addressed. The person with a disability and terminal illness needs resourced, seamless, person-centred care. They must have a choice about where to receive their care. If the person with a disability chooses to be in their own home environment then they may be cared for by their carer/s (family/friends), palliative care nurses and other members of the multidisciplinary team of experts.

Communication programs are required to inform the person with a disability and their carer/s of availability of palliative care community packages. These could be targeted to the final days, stabilisation, caregiver respite, complex community care, or, a specific package to meet the needs of the individual. If the person with a disability is in a residential or group home, they should ideally be able to remain in their “home” maintaining their lifestyle and contact with familiar people in their life, whilst receiving quality palliative care.

Services are required which are sensitive to the specialist needs of people with disabilities. The level of need may vary depending on the individual’s unique disability and maintaining functionality within their abilities alongside the need for palliation. Acceptable and specific models of care and treatment must be developed and implemented that meet the requirements of the person’s disability.

Palliative care services need to be available in the location that best suited to the community. This means care should be provided in acute settings, in the community - both in the home and in aged care facilities, and by specialist services - both in-patient and in-reach supports to those services.

These are areas where there are current service and funding gaps, particularly in relation to the availability of after-hours nursing services and capacity to cater for changes in care needs on-site, that must be urgently addressed.

Segmenting the current Home and Community Service system based on the age of the client, needs of the client, their carer and the providers.

The QNU is concerned that further fragmentation of services based on the age of the client may impact negatively on the client and their carers. This is a complex matter, but in the experience of our members, it is very difficult for people aged under 65 to receive adequate services. The criteria for the Department of Communities to accept ‘appropriate’ referrals is unclear which delays service delivery and often results in the individual accepting aged care services. This segmentation is confusing and distressing for the person and their carer and has the potential to create additional gaps.

Palliative care funding for ‘hands on’ care is only available in the last few weeks of life potentially creating a further service gap. Organisations such as Blue Care and Anglicare offer domiciliary services but it is limited and is not available after hours or link directly to medical consultants.

Discussions around funding commonly focuses on primary and secondary specialist services rather than the type of care the individual requires. The funding model drives the care, not the needs of the client. The QNU supports a funding model that allows flexibility as the current restrictions can interfere with continuity of care. The model should not include demarcations based on age where one funding source ends at 65 and then another applies or where funding is only available for a stage of the illness and not for end of life care.

Recommendations

The QNU calls on the Committee to recommend that the government:

- Develops a statewide plan for palliative care services that recognises the needs of the individual as central to the type of care rather than the funding source;
- Endorses and implements palliative care case conferences as best practice;
- Provides all aged care nursing staff with systematic education in the principles and practice of a palliative approach;
- Broadens the scope of, and adequately funds, services such as the nurse-led Hospital in the Nursing Home team at Royal Brisbane and Women's Hospital;
- Implements communication programs to inform a person with a disability and their carer/s of availability of palliative care community packages;
- Employs more Nurse Practitioners in the area of palliative care.

References

- Australian Nursing Federation (2012) *Submission to Senate Community Affairs Committee in response to the Inquiry into Palliative Care in Australia.*
- Australian Nursing Federation (2012) *Nursing care of the person with a terminal illness ANF Policy.*
- Palliative Care Nurses Australia Inc Australia (2012) *Submission to the Senate Standing Committee on Community Affairs Inquiry into the Provision of Palliative Care in Australia.*
- Tuffrey-Wijne, I. (2003) 'The palliative care needs of people with intellectual disabilities: a literature review', *Palliative Medicine*,. 17. pp. 55-62.
- Tuffrey-Wijne, I. et al. (2008) 'Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals' *Palliative Medicine*, 22. pp. 281-290.