

Palliative Care Role Delineation Framework

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Summary NSW Department of Health commissioned the Palliative Care Association of NSW to conduct a review of palliative care services in the State. The review revealed a high degree of variability in the structure and resourcing of palliative care services in the NSW health system, reflecting similar variability in other states. The review found it was difficult to benchmark or to plan services collaboratively because of differences in structure, organisation and service. The findings of the review were subsequently considered at statewide palliative care workshops in NSW. The workshops supported the need for a framework to classify palliative care services according to role and resource capability. Role delineation frameworks provide consistent and common language to describe and differentiate health care services. They are used to facilitate strategic planning at area, regional and state levels. They can also be used to support program and service level evaluation, quality and research activity.

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Affiliated Health Organisations - Non Declared, Affiliated Health Organisations - Declared, Community Health Centres, Divisions of General Practice, Government Medical Officers, NSW Dept of Health, Public Health Units, Public Hospitals

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Role Delineation Framework

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EXECUTIVE SUMMARY

All people in NSW with life-limiting illness, their carers and their families should have access to high quality, compassionate and well-coordinated systems of care.

NSW Department of Health commissioned the Palliative Care Association of NSW to conduct a review of palliative care services in 2003. The review revealed a high degree of variability in the structure and resourcing of palliative care services in the NSW health system. The review concluded that it would be difficult to benchmark or to plan services collaboratively because of differences in structure, organisation and service.

The findings of the review were subsequently considered at statewide palliative care workshops in NSW. The workshops supported the need for a framework to classify palliative care services according to role and resource capability.

As a result, the Role Delineation Framework was developed to provide consistent and common language to describe and differentiate palliative care services. A logical structure to describe palliative care services provides Area Health Services and the NSW Department of Health with a planning tool to develop equitable use of highly valued services. It is based on a review of literature; other State policies and extensive consultation with palliative care services in NSW.

The Role Delineation Framework outlines the relationship between specialist and primary care services, and defines three levels of specialist palliative care services in terms of their resources and capability. It also outlines appropriate access to support services at different levels. It expands on the three components of palliative care delivery outlined in the NSW Palliative Care Framework (2001):

- Generalist providers,
- Specialist providers, and
- Community support services.

The framework allows these sectors to conceptualise how patients can readily move between services when care needs escalate or when needs are stabilised.

It recognises the unique contribution each sector makes to system wide responses to the needs of people with life-limiting illness, carers and family and can guide negotiations between palliative care services and other health care providers, such as aged care and oncology services, to reduce duplication of effort and to improve outcomes for individual patients and their families.

In 2006/2007 the NSW Department of Health allocated \$1.49M recurrently to Area Health Services and the Children's Hospital at Westmead to develop and implement strategic reforms to palliative care services.

The NSW Palliative Care Framework is shortly to be updated to support these strategic reforms and will include the Role Delineation Framework. Together these frameworks will facilitate strategic planning and assist with program and service level evaluation, quality and research activity. They will guide Area Health Services in the development of complimentary, appropriate and efficient palliative care services to ensure that all patients are able to access the support they require to meet the challenges presented by life limiting illness.

Purpose

The purpose of this Guideline is to:

1. Provide people with life-limiting illness who have little or no prospect of cure, their family, friends and their carers with an evidence-based service structure for the management of people with life-limiting illness in the acute hospital setting, rehabilitation and community care settings.
2. Identify where services may be tailored to suit local needs, resources and individual circumstances.
3. Facilitate equitable care for people with life-limiting illness their family, friends and their carers across NSW, and
4. This Guideline represents a statement of best practice in the management of people with life-limiting illness. It is not intended to replace the clinical judgement of individual health professionals.

Scope

In this document, the primary *palliative care service* refers to the group of services, which cover the continuum of care required for all people who are experiencing a life-limiting illness with little or no prospect of cure. This incorporates General Practitioners, community nursing and allied health staff. A *specialist palliative care service* includes clinicians with recognised skills, knowledge and experience in palliative care.

The specialist team at a minimum includes:

- Director of Palliative Care on an area basis.
- Medical practitioner with qualifications and/or experience in palliative medicine.
- Clinical Nurse Consultant with qualifications in palliative care nursing.
- Nurse Practitioner (Palliative Care).
- Social worker with palliative care expertise.
- Formalised access to bereavement support.
- Formalised access to pastoral care.

In order to ensure access to expanded multi-disciplinary care where required to meet individual patient's needs, the specialist team would have formalised network links to:

- Primary Care Providers
- Higher level Specialist Palliative Care providers
- Residential Aged Care facilities, and
- Care Support Services.

The composition of the team at each phase within the palliative care service should be appropriate to the type of service being provided and the needs of the patient. The patient and/or their carer is to remain at the centre of all decision-making and be an integral member of the team that is providing the care.

Access is a major barrier to equity of service provision for those receiving palliative care and is influenced by geographic, economic and socio-cultural factors. Challenges

for rural and remote services are particularly apparent where resources are often limited. This Guideline may include recommendations that cannot be resourced in all regions of NSW. In such instances it is the intention of this guideline that procedures may need to be modified to address the resource issue and local solutions developed to ensure that best practice and optimal patient outcomes are maintained.

BACKGROUND

Defining Palliative Care

Palliative care is specialised health care provided for people with life-limiting illness who have little or no prospect of cure. The primary treatment goal is quality of life. The World Health Organisation describes palliative care as:

“...an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychological and spiritual. Palliative care:

- *Provides relief from pain and other distressing symptoms*
- *Affirms life and regards dying as a normal process*
- *Intends neither to hasten nor postpone death*
- *Integrates psychological and spiritual aspects of patient care*
- *Offers a support system to help the family cope during the patient's illness and in his or her own bereavement*
- *Uses a team-based approach to address the needs of patients and their families, including bereavement counselling if indicated*
- *Enhances quality of life, and may also positively influence the course of an illness*
- *Is applicable early in the course of an illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”*

One population – three levels of need

Each year in Australia 64,000 people experience an anticipated and expected death. Of these patients approximately half (37,500) are currently seen by specialist palliative care services.

A clear and shared understanding of the needs of the entire population of patients with life-limiting conditions, including their needs for primary and specialist palliative care, will assist in developing transparent and unambiguous access policies and referral criteria, ensuring that patients are able to move between care providers based on assessed clinical need with little disruption to their clinical care or support.

Figure 1 represents the total population of patients who die each year of life-limiting illness. It demonstrates, in broad population terms, the types of care they will require. Best practice evidence suggests that palliative care should be available from the point of diagnosis, although it is accepted that the level of patient need may fluctuate during the period from diagnosis to eventual death. Systems of care need to be sufficiently

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flexible to ensure that services remain aligned to the changes in level of need and respond appropriately.

For those patients whose death can be anticipated, dying is not so much a limited and final 'event' as it is a process - a process that for most patients begins when a diagnosis of a life limiting illness is made. For the majority of palliative care patients this diagnosis is likely to be a diagnosis of cancer, although increasing numbers of patients with non-malignant diseases are seeking end-of-life supportive care.

Empirical evidence suggests that within the total population of people living with life limiting illness, the majority will experience a relatively uncomplicated, though potentially distressing trajectory following the point of diagnosis (Group A). These patients mainly receive services from primary care providers¹.

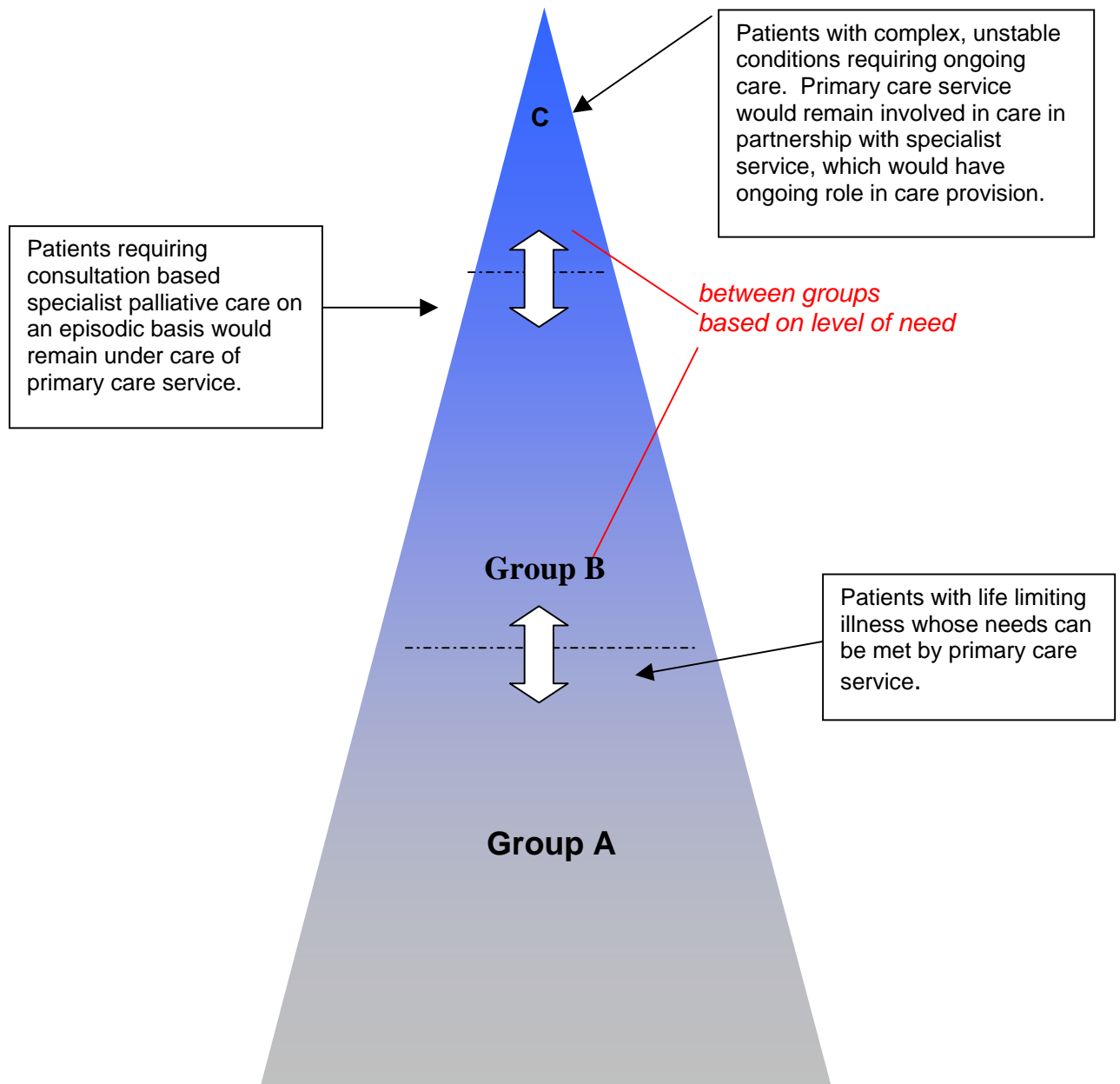


Figure 1: Health care services and patients with a life limiting illness

¹ For the purposes of this document primary care providers is used to include general practitioners, generalist community nurses and allied health staff and other specialist services/professions (e.g. medical oncology, aged care, general medicine) working in community, residential aged care facilities or acute care hospitals. Collectively these primary providers represent the first contact carers at the time of diagnosis. These services/professional may have existing relationships with the patient, or be providing interventional care in conjunction with more palliative approaches.

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Some patients from Group A may experience episodes of increased distress associated with physical, emotional or social consequences of their illness (Group B). These episodes are of variable duration and intensity but require additional support or intervention from professionals skilled in palliative care. When appropriately managed these patients are frequently stabilised and may be referred back to primary care services for ongoing care. Group B patients require consultation based care from specialist services.

A third, smaller subset of people (Group C), will experience problems of high intensity, complexity and/or frequency. The needs of these patients generally exceed the capacity of primary services. These patients will receive direct care from the specialist service, although the primary care service will remain involved. Once again, should the problem be resolved, the patient may move back to less intensive care arrangements (i.e. Group A or B).

Improving outcomes at a population and individual patient level requires programs that target large sections of the community - not only those currently affected by a life limiting illness. Public health and health promotion activities target all members of the community with the goal of reducing further burden and distress.

Disseminating and practising public health initiatives is the responsibility of all health services, with specific responsibilities for public health units, health promotion services, generalist service providers and specialist palliative care services.

ROLE DELINEATION FRAMEWORK

The role delineation framework describes three components:

1. The relationships and roles of Primary care services and Specialist care providers caring for patients with life-limiting illnesses.
2. The classification of specialist palliative care services into three levels in terms of their resources and capability.
3. Access to community support services.

1. Relationships and Roles

- a. The role of primary care services

When diagnosed with a life limiting illness most, but not all, patients will have an existing relationship with a general practitioner and a medical specialist such as a medical oncologist, renal physician or surgeon.

These health care services and professionals are considered 'primary' or 'first contact' services. For most patients, their carers and families, the relationship with a general practitioner will continue until the death of the patient and beyond. For many, the relationship with their medical specialist will also continue for an extended period following the diagnosis of a life limiting illness.

The role of the primary care service, whether a general practitioner or another medical speciality, is fundamental to the provision of high quality care for people with life limiting illness. The care currently provided by primary care providers is central to an integrated approach to caring for people with life-limiting illnesses.

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The Role Delineation Framework acknowledges and makes visible the significant contribution being made by these primary care providers, in particular the care and services provided by GPs, community nurses and the staff of residential aged care facilities and acute care facilities, allied health staff and staff working in acute care health facilities.

The role of primary care providers is to provide supportive care, including pain and symptom control, social, spiritual and emotional support, education and bereavement risk assessment for patients, care givers and family members.

Primary care givers will provide on-going support, from diagnosis to death of the patient and beyond. Where primary care services are primarily responsible for care of patients with life-limiting illness they should ensure that formal links have been established with allied health, home care and other support services required to meet the patient's holistic needs.

In addition to their non-palliative care responsibilities, primary care services have a responsibility to:

Undertake a holistic assessment of patients diagnosed with life limiting illness at the point of diagnosis and on an ongoing basis;
Implement and undertake best practice referral policy and procedures; and
Meet primary care standards for competency in the primary care management of patients with life limiting illness. These standards should include competency in pain and symptom management, emotional and spiritual assessment and support, and management of loss and grief. These are sometimes referred to as palliative approach skills.

b. The role of specialist palliative care services

The role of the specialist palliative care service supports and complements the care provided by primary care services. In particular, specialist palliative care services provide care for patients with complex or unstable symptoms or to meet other high level needs associated with a life-limiting illness.

Specialist palliative care staff will, in general, have formal qualifications in palliative care (medical nursing or allied health) or adequate experience where there is an absence of a formal training program.

Specialist palliative care services provide interdisciplinary assessment, consultation and when required ongoing care for patients in conjunction with their primary care service providers and the patient's caregivers. Specialist care may be episodic and ongoing partnerships with primary care providers are necessary to ensure the development of a single system of care with seamless referral and case management of patients.

Specialist palliative care services have a responsibility to:

Undertake comprehensive interdisciplinary assessment of patients with life- limiting illness referred to the service. The assessment should include the needs of caregivers and family members:

Establish formal links and referral pathways and processes with primary care services and other specialist services that may be required to meet patient needs:

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Develop formal links with pain services, radiotherapy, anaesthetics and other tertiary acute care services:

Provide consultation-based assessment and care as appropriate for patients with life-limiting illness, their caregivers and family. Consultation based services are provided in partnership with primary care services; and

Provide ongoing care for patients with complex needs associated with life-limiting illness, in partnership with primary care services.

2. The Classification of Specialist Palliative Care Services

The second component of the framework is the classification of palliative care services in NSW according to resourced capability and available expertise. It outlines a number of levels of specialist palliative care services. Each level describes and reflects the complexity of clinical activity undertaken by a service and specifies the staff profile, support services and other requirements recommended to ensure that effective, high-quality services are available to meet the needs of patients and their carers and families.

This component of the Role Delineation Framework provides health service planners, researchers, funders and service providers with a consistent, structural framework to describe the characteristics of specialist palliative care services, and to align those expectations with resourced capability.

The Framework proposed has been developed for application in community and/or inpatient settings, and can be used to describe a service or a network of services providing care to a defined population of patients with life-limiting illness. It should be applied at a population level and should be based on a stratified analysis of need within specific populations, for example the number of patients expected to require primary care or specialist palliative care services at level one, two or three.

Resource profiles are broadly aggregated to provide three service type groups that reflect minimal, moderate and high resource levels, and therefore expected capability levels. It is not a mechanism for grading services, but rather a tool for grouping like services in terms of their resources and capability.

Services at a local level will generally need to plan to meet the needs of patients in each of the three primary target groups. State wide service planning will need to be undertaken to establish formalised relationships between specialist palliative care resource levels to maximise access to highly specialist palliative care. Level three services will also need to establish and implement internal 'care escalation' models to ensure that patients whose needs are less complex continue to receive care appropriate to, and consistent with, their level of need.

Efficient use of resources is dependent on matching service level to patient need at a population *and* individual patient level. Analysis of the needs of the three distinct but overlapping sub-populations of palliative care patients will also need to be undertaken to ensure equitable use of these highly valued but restricted services.

Table 1: Resource Capability Matrix

Level	Capability Statement	Resources
Specialist Palliative Care Level 1	<p>Level 1 Specialist Palliative Care services provide a specialist palliative care consultation and direct care service to patients whose needs exceed the capability and resources of primary care providers. Level 1 specialist palliative care should be available locally as a minimum for all patients with life-limiting illness.</p> <ul style="list-style-type: none"> ▪ Provides specialist palliative care for patients and their families where assessed needs exceed the resources capability of primary care providers. ▪ Provides assessment and care consistent with the needs of the patient, caregiver and family and within available service capability and resources. ▪ Provides consultation and support to primary care services managing the care of people with life-limiting illness in community, acute care hospitals and residential aged care facilities. ▪ Provides ongoing care to patients with complex, unstable conditions not restricted to physical symptoms but including psycho-emotional, social and spiritual problems. ▪ Provide 24/7 specialist support and advice for registered patients and carers, including patients in residential aged care facilities and acute care hospitals. ▪ Provides education to primary care providers. ▪ Participates in education programs to develop specialist palliative care skills. ▪ Participates in research and quality activities. ▪ Has access to designated/dedicated inpatient palliative care beds. 	<p>Indicative Staffing:</p> <ul style="list-style-type: none"> ▪ Director of Palliative Care on an area basis. ▪ Medical practitioner with qualifications and/or experience in palliative medicine. ▪ Clinical Nurse Consultant with qualifications in palliative care nursing. ▪ Nurse Practitioner (Palliative Care). ▪ Social worker with palliative care expertise. ▪ Formalised access to bereavement support. ▪ Formalised access to pastoral care. <p>Links: Formalised network links to primary care providers and Level 2 and/or 3 Specialist Palliative Care providers Formalised links with residential aged care facilities. Formalised links with core support services (see Support Service List) to ensure access to expanded multi-disciplinary care where required to meet individual patient’s needs.</p>

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<p>Specialist Palliative Care Level 2</p>	<p>As for Level 1 Specialist Palliative Care Services (above) In addition a Level 2 service would;</p> <ul style="list-style-type: none"> ▪ Provide support and consultation to Level 1 services within local area for patients who have complex problems (physical, emotional, social or spiritual). ▪ Provide or contribute to education to support Level 1 specialist providers as appropriate. ▪ Participates and/or provides leadership in collaborative research activities. ▪ Capability for registrar training under supervision of Fellow. 	<p>Indicative Staffing:</p> <ul style="list-style-type: none"> ▪ Director of Palliative Care on an Area basis. ▪ Medical specialist(s) with specialist qualifications in palliative medicine (Fellow of Chapter of Palliative Medicine) and/or ▪ Medical practitioner(s) with specialist qualifications in Palliative Medicine. ▪ Clinical Nurse Consultant with specialist qualifications in palliative care. ▪ Nurse Practitioner (Palliative Care). ▪ Clinical nurse specialists / Registered nurses with formal qualifications in palliative care ▪ Specialist allied health staff with a direct report to Director Palliative Care, including but not limited to: <ul style="list-style-type: none"> - Social work - Pastoral care - Physiotherapist - Bereavement support - Pharmacist ▪ Volunteer/ Volunteer Co-ordinator <p>Links: Must have formal links with primary care providers in their local area and with Level 3 Specialist palliative care service for patients with complex needs. May have links to a Level 1 Palliative Care service. Has formal links with Universities as appropriate to role and function.</p>
<p>Specialist Palliative Care Level 3</p>	<p>As for Level 2 Specialist Palliative Care Service (above) In addition a Level 3 service would;</p> <ul style="list-style-type: none"> ▪ Provide for the needs of patients with complex end of life care issues/problems referred either directly or through Specialist Level 1 or 2 services. ▪ Provide consultation-based service for Level 2 Palliative Care Services outside of local area (e.g. for rural or remote area services) through formal network agreements. 	<p>Staffing:</p> <ul style="list-style-type: none"> ▪ Director of Palliative Care on an Area basis. ▪ Medical specialist(s) with specialist qualifications in palliative medicine (Fellow of Chapter of Palliative Medicine) and/or ▪ Medical practitioner(s) with specialist qualifications in Palliative Medicine. ▪ Clinical Nurse Consultant with qualifications in palliative care.

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	<ul style="list-style-type: none"> ▪ Undertake lead role in education and research in palliative care. Has formal links with academic units. ▪ Con-joint appointment of senior clinical staff. ▪ Capability for registrar training under supervision of Fellow 	<ul style="list-style-type: none"> ▪ Clinical Nurse Specialist(s) with qualifications and experience in palliative care nursing. ▪ Registered nurses with experience/qualifications in palliative care. ▪ Expanded specialist allied health staff with a direct report to Director Palliative Care, including but not limited to: <ul style="list-style-type: none"> - Speech therapist - Dietician ▪ Pastoral Care with experience/qualifications in a field relevant to palliative care. ▪ Volunteer/ Volunteer Coordinator. <p>Links: Formal links with primary palliative care providers (local). Formal links with Level 1-2 specialist palliative care services to provide consultation based care and referral for patients with complex needs.</p> <p>Formal links to other tertiary services/specialties e.g. anaesthetics, pain service.</p> <p>Links to University, Schools of Medicine, Nursing and Allied health. Conjoint appointment of senior clinical staff.</p>
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3. Access to Community Support Services

Both primary care and specialist palliative care services require access to a range of support services to enable them to meet the needs of patients with life-limiting illnesses. It is not necessary for these services to be provided as part of palliative care services, but rather that they should be available when required to meet the needs of individual patients.

A number of support services are essential to both primary care and specialist services. These include bereavement services; Home and Community Care (HACC) and home care services, occupational therapy, pain clinics, social work and respite services.

The availability of volunteer support services are necessary for both primary care and specialist services to ensure that patient and family needs could be met, although clearly there are different issues related to their co-ordination and support in the primary care and specialist areas.

It is essential that appropriate referral and access mechanisms be in place so that these support services can be accessed if and when they are required. Access has been determined on the basis of consistency with the capability statement of each of the three service levels. Access to some support services is seen as essential for all palliative care services, others are seen as relevant for level two and three services. **Table 2** sets out these requirements.

Support Service	Primary	Specialist Palliative Care Services		
		Level 1	Level 2	Level 3
Anaesthetics				X
Bereavement	X	X	X	X
Data Manager			X	X
Dentist			X	X
Diagnostic Imaging	X	X	X	X
Dietitian	X	X	X	X
Diversional Therapy	X	X	X	X
HACC	X	X	X	X
Home Care	X	X	X	X
Mental Health	X	X	X	X
Music Therapy		X	X	X
Occupational Therapy	X	X	X	X
Pain Clinic			X	X
Pastoral Care	X	X	X	X
Pathology	X	X	X	X
Pharmacy	X	X	X	X
Physiotherapy	X	X	X	X
Podiatry	X			
Psychology			X	X
Psychiatry			X	X
Respite Care	X	X	X	X
Social Work	X	X	X	X
Speech Pathology			X	X
Volunteers/Volunteer Coordinator	X	X	X	X

Table 2: Support services required by palliative care patients

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In addition to the services listed in **Table 2**, support services and roles including equipment hire, clinical supervision, business manager, quality manager, health promotions, play therapist, interventional radiologists, aged care assessment team, transport and Aboriginal health are also important in the provision of palliative care.

It is not suggested that these services be provided in conjunction with palliative care services, but that they be available for individual patients when required.

CONCLUSION

The Role Delineation Framework has been developed as a guide to address the current variability in NSW palliative care services. Application needs to be undertaken strategically to allow services time to gain the required capabilities to meet community need.

The components are designed to be used together to better co-ordinate statewide and population based planning for palliative care services. They can also be used to guide negotiations between palliative care services and other health care providers - for example, aged care services and oncology services - to reduce duplication of effort and improve patient and family outcomes.

The application of the Role Delineation Framework has the potential to develop a consistent standard for the delivery of palliative care services in NSW. Effective networking of services of differing capability and resources will help to ensure that *all* palliative care patients in NSW will have access to services appropriate to their level of need, regardless of their diagnosis or location.

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