

# OVERVIEW OF PALLIATIVE CARE SERVICES IN NEW SOUTH WALES 2006

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*A report commissioned by the Cancer Institute NSW*

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## Introduction

This report provides an overview of specialist<sup>1</sup> palliative care services in New South Wales. The description provided is a snapshot of the structure of services at a point in time – the project commenced in August 2006 and was completed in March 2007. The nature of services is continually changing and some programs changed even before this report had been finalised.

Each Area Health Service (AHS) is divided into clusters, zones or networks within which the Palliative Care service operates. In many instances these clusters, zones or networks reflect the Area Health Service structure which existed prior to January 1 2005.

An important finding of the review was the variation in service delivery models for palliative care across the State.

## Methodology

To gather the information for the overview, a survey instrument was developed and sent to the directors of each service and an interview time scheduled.

Primary information was obtained from the palliative care service director in each sector/cluster/zone/network and in some cases, the palliative care clinical nurse consultant. Interviews were either face-to-face or by phone. If the director or palliative care clinical nurse consultant was unable to answer some questions, the consultant was generally referred to another information source.

AHS reports were returned to the director to confirm accuracy and obtain additional information if required. In May 2007 draft reports from the individual AHSs were sent to the directors for final review.

## Key findings

### AHS organisational structure

In all of the metropolitan AHSs there are at least two, and in one case three, discrete palliative care services. They each have their own service director.

In three of the four metropolitan AHSs, the separate service directors report clinically to the Area director of cancer. In some instances the community palliative care services are separately managed by the primary care and community health services. In two of the regional/rural AHSs, palliative care is in primary care and community health services and in the other two regional/rural AHSs, it is part of cancer services.

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<sup>1</sup> 'Specialist' palliative care services are defined as those services that are 'not primary'. Primary care services that provide care to people at the end of their life are not quantified in this inventory but are identified in terms of how the specialist palliative care services interact with them.

## Models of palliative care

There is considerable variation in palliative care models utilised across NSW, depending on location resources and historical influences. In metropolitan AHSs, the typical palliative care model of service consists of:

- designated inpatient beds either in acute or sub acute public hospitals or in a third schedule hospital
- inpatient consultations in all hospitals in the AHS (including private hospitals)
- a community medical and/or nursing service.

In some AHSs the palliative care medical specialists see patients in their own homes; the extent of medical involvement in the community varies from one metropolitan AHS to another. The specialist palliative care nurses provide a consultative service to the community nurses who, with the GP, are the patient's primary care provider. The specialist palliative care nurses also provide a consultative service to the residential aged care facilities, where the primary care providers are the residential aged care facility staff and the GP.

In regional/rural AHSs there may be some designated palliative care beds within district hospitals. In all regional/rural AHS the local community nurses and GPs are supported by specialist palliative care nurses.

When a patient is admitted to a designated palliative care bed in a metropolitan public or third schedule hospital they are generally under the direct care of a palliative care physician. However, in most acute public and private hospitals, palliative care medical specialists see patients on a consultative basis so the patient is usually admitted under the care of another specialist. In some acute public hospitals, patient care is shared between the treating specialist and the palliative care physician. Occasionally the palliative care physician takes over patient care in an acute hospital when active treatment has ceased. Palliative care patients in the community are either under the direct care of the GP or their care is shared by the GP and palliative care physician.

Variation in models of palliative care across NSW is demonstrated by the difficulty in acquiring a clear picture by AHS of the proportion of patients under the direct care of palliative care physicians, the proportion of consultations and the proportion of shared care patients.

In regional/rural AHSs palliative care patients are generally admitted to palliative care beds under the care of a GP visiting medical officer (VMO) who would be in close contact with the visiting medical specialist.

## Hours of service

The extent and nature of after hours cover by specialist palliative care services is variable. In metropolitan AHSs, medical specialists are on call for the inpatient units and for phone consultation to the specialist palliative care nurse or GP. They do not generally make home visits after hours.

There are variable arrangements in all AHSs for nursing after hours cover including:

- a specialist palliative care nurse on call 24 hours a day for telephone consultation with another health care provider or the patient's family/carer or to do a home visit
- a specialist palliative care nurse on call if it is anticipated that they may be needed (common in regional/rural AHSs)
- a specialist palliative care nurse on call for extended hours for phone consultation or home visit.
- no specialist palliative care nurse on call after hours. Calls diverted to a hospital ward/unit where staff have details of all registered palliative care patients
- community generalist nurse on call 24 hours a day.

## Staffing

Overall 370 FTE positions provide palliative care in NSW including 89 medical staff, 179 nurses and 100 allied health staff.

A clear finding of the study was the different model of palliative care practiced in rural areas due to lower population numbers over larger areas. The main difference relates to the higher number of specialist nursing staff in rural /regional areas compared to specialist medical staff.

### *Medical staff*

There are GP VMOs in both metropolitan and regional/rural AHSs. Corresponding to higher population numbers it follows that most of the registrar positions are in metropolitan areas as the number of staff specialists is higher in these areas. Specialist outreach services are provided for rural palliative care patients in various AHS, through agreements with metropolitan hospitals. These are rarely formalised.

### *Nursing staff*

There are a total of 54.4 palliative care cancer nurse coordinator (CNC) positions in NSW with approximately twice the number in metropolitan units. There are three palliative care nurse practitioner positions across the state. Interestingly in rural areas the numbers of clinical nurse specialist (CNS)/registered nurse (RN) positions working in palliative care were higher. The number of specialist nursing positions in rural NSW is proportionally higher than for metro areas considering population numbers

### *Allied health staff*

Most allied health professionals working in palliative care in a specialist capacity are located in metropolitan facilities. In rural areas allied health for palliative care patients appears to be delivered in a more generalist capacity.

### *Other staff*

Designated palliative care positions outside medical and nursing positions including nurse manager positions, data managers, administrative assistant positions and research assistant/project officer positions were also identified. These were predominantly in metropolitan settings.

## **Services/facilities**

### *Beds*

A 'designated palliative care bed' was present in a variety of settings with varying degrees of specialist palliative care support. In metropolitan AHSs designated palliative care beds included:

- Beds in acute hospitals that have been designated within a larger ward and where the actual number of palliative care patients in that ward can vary at any time. The nursing staff on that ward do not necessarily have palliative care training; however the medical staff who admit patients to those beds are palliative care trained.
- Beds in an acute public hospital in a quarantined ward with palliative care trained staff to which only palliative care patients can be admitted, regardless of the need for beds through the emergency department.
- Beds in a stand alone unit within the grounds of an acute public hospital with trained medical and nursing staff and to which only palliative care patients can be admitted.
- Beds in a third schedule hospital with palliative care trained medical and nursing staff and to which only palliative care patients can be admitted.
- Beds in a sub acute public hospital with palliative care trained medical and nursing staff and to which only palliative care patients can be admitted.

A total of 348 designated palliative care beds statewide were identified with approximately 80 per cent in metropolitan AHSs. This is not a comprehensive measure as it does not include beds in acute hospitals used by patients where palliative care teams have taken over patient management.

In regional/rural AHSs designated palliative care beds are largely in third schedule hospitals. The nursing staff for these beds mostly have palliative care training and/or experience. As there are limited palliative care physicians in regional/rural AHSs these patients would probably be admitted under the care of GP VMOs who would be in communication with the visiting medical palliative care specialist. In most regional/rural hospitals palliative care patients are admitted to a single hospital room, with consultancy services provided by specialist palliative care nurses.

### *Inpatient consultation*

All AHSs provide medical and nursing inpatient consultation in all acute public and private hospitals. Palliative care nursing services also provide a consultative service to residential aged care facilities.

### *Outpatient clinics*

There is some variation in the provision of formal outpatient clinics. In some services they are seen as a very efficient way of seeing as many patients as possible. In other services they are more informal and the palliative care medical specialist may arrange for a patient to come and see them in their consulting rooms at a mutually convenient time. Some palliative care specialists would rather try to see patients at home.

### *Community service*

Most palliative care services in NSW have a community service which is usually a consultative nursing and in some metropolitan AHSs, a medical consultative service. The medical and nursing palliative care specialists provide a consultative service to the community nurses and the GP who are the primary care providers.

### *Day hospital*

Some metropolitan palliative care services have day hospitals. One palliative care service in a regional/rural AHS has day care, which is run by volunteers. The amount of clinical services received as part of a day hospital visit varies considerably between day hospital/care services.

### *Access to support services*

Most palliative care services have access to a range of support services from acute hospitals. In the metropolitan and regional/rural AHSs these include diagnostic radiology, pathology and pharmacy. Anaesthetic services (pain management and interventional anaesthetics) are mostly only available in metropolitan AHSs. Some inpatient palliative care services do not have their own designated allied health staff and are dependent on allied health support from the general hospital allied health departments. In the absence of service agreements between the palliative care service and the allied health department, the palliative care services have no control over their access to allied health staff and this may fluctuate. In the community, in both metropolitan and regional/rural AHSs, access to allied health services varies from one palliative care service to another.

### *Volunteers*

Most palliative care services have volunteers. The number of volunteers varies dramatically from none or few, to over 200 in one metropolitan service. The average number is between 30 and 40 volunteers per service. Some services can only manage a certain number at any one time so they may have volunteers waiting to become involved. The tasks performed by volunteers vary between services and include activities such as flower arranging and plant watering, sitting with patients, visiting patients in their homes. In a number of palliative care services, volunteers provide bereavement support, after attending a counselling course.

Palliative care services provide training programs and support for their volunteers. The training programs vary between services. In one Palliative care service volunteer training consists of four sessions whereas in another service in the same AHS, it consists of 12 sessions.

### *Private services*

Most palliative care services provide inpatient medical consultations to patients in private hospitals in their service area. However, there are no formalised agreements between AHSs and private hospitals. Sometimes the nursing and/or allied health staff from the public palliative care service are also requested to consult patients in private hospitals, without reimbursement by the private hospital.

### *Paediatrics*

Both the Sydney Children's Hospital (SCH) and the CHW provide palliative care services. Most community palliative care services see some children each year. They are usually cared for in consultation with one of the State's three children's hospitals and/or the child's paediatrician as well as the local community services and the family GP.

### *Equipment*

There is no standard approach to the provision of palliative care equipment across NSW. Even within a service, there may be more than one approach. Some services obtain their equipment from a central pool; others obtain it from a specialised palliative care pool. Some equipment is centrally based and specific palliative care equipment is held by the palliative care service. In some AHSs it is the responsibility of the palliative care staff to clean, maintain, deliver and pick up equipment. In other AHSs the cleaning and maintaining is the responsibility of the equipment pool staff, and the delivery is on a contract basis. In some cases, the palliative care staff deliver some of the smaller items (syringe drivers) and a contractor delivers the larger items (beds). Some AHSs hire major equipment items, which means the cleaning, maintenance and delivery is the responsibility of the hiring company. Access to oxygen in terms of saturation requirements and responsibility for payment varies between AHSs.

## **Cancer and non-cancer patients**

The ratio of cancer to non cancer patients by service varies from service to service with the highest proportion of cancer patients at around 95 per cent and the lowest around 70 per cent. The average is around 85–90 per cent. There are variations within services with a higher non-cancer workload in the community compared to inpatient units. In some services there has been an increase in the proportion of non cancer palliative care patients over the past few years.

## **Policies and procedures**

All services have some policies and procedures but the extent and nature of those policies and procedures varies. In some AHSs the palliative care service operates within the policies and procedures of the facility/community health centre where staff are working, while others have palliative care specific policies and procedures for the zone/cluster. Some AHSs are working towards Area-wide palliative care specific policies and procedures.

Most AHSs have service agreements with third schedule providers of palliative care services but not with private services. All services have quality assurance procedures.

All services are accredited as part of the Australian Council on Healthcare Standards (ACHS) accreditation for the facility/community health centre from which they operate.

Community death certification is sometimes a problem because GPs are increasingly not available after hours.

All AHSs have formal or informal staff de-briefing and some palliative care services pay for outside clinical supervision.

### **Training and education**

Most palliative care staff have access to training and education. Palliative care staff in all services provide education about palliative care to non-palliative care staff in both hospital and community settings. Medical, nursing and allied health students come on placement to most of the metropolitan AHSs.

### **Conclusion**

This report provides an overview of specialist palliative care services in NSW. Some of the information, especially in relation to patient numbers and budget, is highly variable and not comparable between AHSs.

The focus and service delivery model of palliative care services across NSW varies due to the historical influences that have shaped their nature and growth. These historical influences include the different backgrounds of people who have been responsible for developing the service, the availability of resources especially the location of third schedule institutions, the impact of Commonwealth funding at various points in time and the role of related services, such as oncology and pain services on the development of palliative care services.