Palliative Care

NEW SOUTH WALES

Palliative Care Framework

A guide for the provision of palliative care in NSW

NSW HEALTH
Better Health *Good Health Care*

Health
Working as a Team
The Way Forward

NSW HEALTH DEPARTMENT

SHPN: (HP) 010014
ISBN: 0 7347 3260 0

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March 2001

Foreword

The NSW Department of Health recognises the importance of providing services that are appropriate to the needs of local populations and that maximise the quality of life of individuals. Palliative care is a relatively new speciality area in health services that has grown in response to the complex range of needs of people with progressive advanced disease or terminal illness.

While specialised palliative care inpatient services are concentrated in the metropolitan areas in NSW, access to appropriate services by the outer metropolitan and rural populations is an important consideration in palliative care service delivery. Growth in demand for palliative care services across the diversity of geographical settings has resulted in innovative models of care being developed and a recognition of the significant role of the community sector.

As services have expanded the Department has worked towards the development of specific policies to provide direction for palliative care service planning and development. The NSW Palliative Care Framework evolved through an extensive consultation process over almost a decade. Its development began with the work of a palliative care working party and a palliative care expert reference group. The 1993 report of the working party articulated principles of palliative care provision, identified targets, advanced a framework to progress the integration of palliative care and mainstream services, and made recommendations to enhance palliative care services. The reference group developed a discussion paper that was widely distributed for comment and provided a basis for a NSW Palliative Care Framework. Finalisation of the Framework has been supported by the wealth of comment provided by representative community organisations, Area Health Services and health care workers employed across the range of hospital and community settings.

The NSW Department of Health is currently implementing through the NSW Government's Action Plan for Health a range of initiatives that will better meet the health needs of both rural and metropolitan populations. It is intended that the NSW Palliative Care Framework will provide guidance for the planning of service delivery and is considered an important step that will promote access to consistent levels of palliative care regardless of where people live. The release of the NSW Palliative Care Framework is therefore timely in view of the range of initiatives in progress as part of the NSW Government's Action Plan for Health.

Michael Reid
Director General

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Introduction

For centuries, hospices have provided care for the sick and dying. As the prevailing traditional medical paradigm in the past centred on curing the patient, hospices provided an important area of care which, at the time, was largely ignored in mainstream health settings.

Attitudes have however changed in terms of the way that health care is generally delivered. The community now has a greater understanding of issues relating to death and dying. Recognition of the rights and needs of the patient, increasing patient education and wider choices of treatment and palliation have significantly reshaped modern philosophies of health service delivery. Although palliative care is focussed on people who are dying, the values inherent in it and some of the services provided are relevant across many areas of health care delivery.

Generally, people with cancer constitute 85-90% of adult palliative care referrals; the remaining 10-15% of referrals are due to other progressive diseases such as advanced organ failure, AIDS and degenerative neurological diseases.

Demand on the palliative care service system is predicted to increase with the ageing of the Australian population and an increased life expectancy. Cancer mortality in NSW has increased from 16% of all deaths in 1972 to about 28% of all deaths in 1998. Projections on deaths up to the year 2001 indicate continued increases in the number of cancer related deaths.

Cancer incidence is also increasing, with the 27,285 new cases of invasive cancer notified to the NSW Central Cancer Registry in 1997. Even after being adjusted for age, cancer incidence rates increased by 17% in males and 11% in females in the period between 1987 and 1997. Cancer incidence projections up to the year 2006 estimate that there will be 31,652 new cases in 2006, an increase of 16% from 1997. These projections take into account the effect of the breast cancer screening program and widescale testing for prostate cancer.

As approximately 50% of patients with cancer will die as a result of the disease, service configuration and resource allocation within cancer services should reflect a balance between cancer treatment and palliative care. The number of people dying from other illnesses and requiring palliative care is also predicted to increase as more people with progressive diseases live to an advanced age.

The exception to the trend is AIDS. At June 2000 there were 1,571 people in NSW with an AIDS defining illness. Although the number has significant implications for palliative care services, over recent years an advance in drug treatments has resulted in many people with HIV/AIDS experiencing improved well-being. While the long term benefits from the new drug treatments remain uncertain, the data at this time suggests a plateau effect rather than an ongoing increase in the number of people with an AIDS defining illness.

These predictions have important implications for health services across NSW. If health services are to meet the overall predicted increase in demand on palliative care particularly within the constraints of limited resources, it is important that each Area Health Service initiate planning for palliative care service delivery. This planning needs to consider general service issues and be integrated with broader health service planning.

In July 1999 the Minister for Health established a NSW Health Council to undertake a review of the State's health care system. The NSW Health Council's findings reinforce the importance of integrating palliative care with broader service planning. For example, the NSW Health Council found that there is a high level of demand on public and private hospital services by people with chronic and complex conditions. Approximately 30% of admissions for these conditions occur through Emergency Departments and are unplanned. As some of this group will be linked to, or appropriate for referral to palliative care services, planning should include the strengthening of linkages between acute and palliative care services, early referral to appropriate services including palliative care and improved management and coordination of care.

These issues have been given recognition in NSW with the launch in 2000 of the NSW Government's Action Plan for Health which is the Government's response to the reports from the NSW Health Council and the NSW Ministerial Advisory Committee on Health Services in Smaller Towns (Sinclair Report).

The NSW Government's Action Plan for Health focuses on the organisation and delivery of health services specifically in the areas of acute care, chronic care, emergency departments and intensive care. Although there is no specific focus on palliative care, the Action Plan will generate significant benefits for people who are dying through the work being undertaken on consumer and community involvement in the health system, funding models and arrangements, the coordination of metropolitan health services, rural health services, quality health care, records management and mental health. For example, people with palliative care needs living outside metropolitan areas will benefit from the guarantee of access to appropriate, quality health care which is one goal for rural health services in the Action Plan.

The combination of outcomes from such initiatives as the NSW Action Plan for Health and specific planning for palliative care will have significant benefits for patients, their family, carers and volunteers. Planning that includes new approaches to service delivery will provide the basis for managing the future of palliative care across NSW.

The following chapters attempt to clarify important aspects of palliative care in NSW including the key elements considered essential to palliative care service delivery, measurement of service activity and outcomes, funding considerations and directions for the future.

Defintion of palliative care

The term 'palliative care' generally refers to activities which aim to ameliorate the effects of progressive, advanced disease or terminal illness and improve the quality of life of the patient, his or her partner, family and friends. Palliative care is generally provided to people of all ages whose condition has progressed beyond the stage where curative treatment is effective and cure is attainable, or to those who choose not to pursue curative treatment.

Palliative care is a concept of care, rather than a particular mode of treatment. It provides coordinated medical, nursing and allied health services including pastoral care services, delivered where possible in the environment of the person's choice. It also provides physical, psychological, emotional and spiritual support for patients and their families, friends and carers. It includes the provision of grief and bereavement support for the families, partners, friends and carers during the life of the patient and following his or her death. Palliative care can be defined as the:

> *" …. specialised health care of dying people aiming to maximise quality of life, and assist families and carers during and after death.*
>
> *Palliative care is holistic, patient and family centred care provided for dying people and their families. Palliative care services acknowledge dying as a physical, psychological, social, spiritual and cultural process that is experienced uniquely by each person and family.*
>
> *Palliative care services are involved in the care of patients and families who are distressed, or who are at risk of being distressed as a consequence of this process. A palliative care service may be provided in collaboration with the patient's primary care team, at any time from the diagnosis of a condition with a limited prognosis up until and after the death of the patient.*
>
> *Palliative care services have an equal and complimentary responsibility to adopt an active role in the building and fostering of positive and informed community attitudes and practices to reduce and minimise the social and personal distress associated with dying in our communities."*[1]

Palliative care service delivery

In NSW palliative care is provided by:

- specialist providers: medical, nursing and allied health staff who have undertaken further study in palliative care or have significant experience in the area
- generalist providers: those clinicians (medical, nursing and allied health) working in other areas of the health system who have a professional involvement with people requiring palliative care
- support services: including those who assist with the processes of daily living, enhancing quality of life, and/or providing emotional and spiritual support.

Palliative care services can be provided in a range of settings including the person's home or other community-based environment such as residential aged care facilities, as well as in inpatient palliative care and acute hospital facilities.

It is important to recognise that people who are dying need to be able to move freely between settings, in response to their changing clinical care or support needs. While individual patterns of care will be dependent on numerous factors, it is widely acknowledged that care is best provided, where possible, within or close to the person's local environment and community[2].

Policy statement

Consistent with the directions set in the Strategic Directions for Health 2000-2005, the NSW Health Department is committed to the provision of services that maximise quality of life for people with progressive advanced disease or terminal illness. The care for those approaching death regardless of their age or their health condition is an integral and important part of health care.

These directions have recently been given support at the Commonwealth level. In October 2000 all Australian states and territories including NSW endorsed a National Palliative Care Strategy which sets out strategies to improve awareness and understanding of palliative care, support quality and effectiveness in service delivery and partnerships in care.

The aim of developing a separate palliative care policy framework for NSW is to strengthen the growth of comprehensive palliative care services across the state. The *NSW Palliative Care Framework* will provide a basis for the planning of service delivery that will promote access, continuity of care and standard levels of care regardless of the location in which the service is provided.

Health services must consider those with palliative care needs in the context of their families and close relationships and be sensitive to the issues raised by culture, values, resources and needs. It is recognised that choice of care must be client rather than service driven and that the entry points into care services may be complicated and vary from individual to individual.

Ease of access and continuity of care for people who are dying can only be achieved through services that provide palliative care across a range of settings. Services must be developed and delivered in a manner consistent with principles underpinning the quality, continuity and choice of care for people who are dying, their carers, partners, friends and families.

Best outcomes can be realised through planning that focuses on client needs and choices, education on palliative care and by strengthening the linkages between acute and specialist palliative care services, and inpatient and community based services including services provided by general medical practitioners, community nurses and allied health professionals. Linkages must encourage referral pathways, consultation on service delivery and effective discharge planning. It is essential that palliative care concepts are promoted and used by all health staff and in all health settings.

Profiles of Area Health palliative care service systems clearly demonstrate the diverse range of service planning and service provision currently in place across NSW. The relatively recent and rapid evolution of contemporary palliative care practice has added to the range of services available particularly in rural areas.

While planning is considered an essential step for the effective delivery of palliative care services in the future, it is recognised that the varying models of care and range of services available will continue to reflect the unique mix of inpatient, community and residential care needs of different community groups and to be influenced by the geographical location of the population and local resources.

This framework has been developed to provide guidance for palliative care service planning and development by Area Health Services as well as the range of services within the palliative care system. The NSW Palliative Care Framework is consistent with the focus on service access and quality service provision set in the National Palliative Care Strategy and in NSW Health Department policy documents.

This *NSW Palliative Care Framework* replaces the 1985 NSW Health Department Guidelines for the Development of Palliative Care Services, and builds on the achievements of the 1993 Report of the NSW Palliative Care Working Party.

Principles of palliative care service delivery

The key principles underpinning the delivery of a comprehensive palliative care service in NSW Area Health Services are:

1. the patient and his or her carers are the focus of care
2. palliative care is provided in a setting appropriate to patient and family needs and wishes
3. palliative care is provided in a culturally appropriate way to accommodate the needs of all patients who require care
4. palliative care can be required by children and young people as well as adults, and service provision should reflect this
5. early access to services that embody the concepts and principles of palliative care impacts significantly upon the wellbeing and quality of life of the patient
6. access to the range of specialised disciplines is required to meet the complex needs of the palliative care patient and their family
7. access to high quality clinical consultation for health care workers and a well developed referral network is essential to high quality clinical care
8. high quality palliative care includes a focus on bereavement support/follow up for the patient and his or her partner, family, friends and informal and formal carers
9. education for the patient and his or her partner, family and carers throughout the continuum of palliative care is an important element of high quality care
10. education for general practitioners and other clinicians, as well as the wider community regarding the role and availability of the palliative care service in the area is an important aspect of the service role
11. identification of the characteristics of clients, services and service outcomes provides a basis for improving the quality and effectiveness of service delivery.

Elements

Key elements for effective palliative care

The following are considered key elements for effective palliative care. These elements should be included in the planning, delivery and evaluation of all palliative care services so that Area Health Services are able to provide the highest possible standards of care for people requiring palliation.

1. A continuum of care for the patient from the point of initial diagnosis. The continuum of care should include physical care to manage pain and other symptoms, as well as psychological, social, spiritual and cultural support.
2. An inter-disciplinary team approach to coordinate medical, nursing, allied health, pastoral care, volunteer and community services to the patient and their carers.
3. Bereavement support and follow up for the patient, their partner, family, friends and carers.
4. A central point for the provision of information to clients, clinicians, the wider public and other health service providers and reporting on the operation of the Area Health Service palliative care service system.
5. Education for General Practitioners (GPs) to enhance their awareness and understanding of palliative care and to involve them in the provision of palliative care in the community.
6. Education for medical and nursing clinicians to increase their awareness and understanding of palliative care and to encourage appropriate patient/carer engagement in the palliative care service system.
7. An enhanced role for volunteers in the care of people who are dying. Volunteers must however be provided with adequate training and support.
8. Strategies that promote access by specific population groups including children/adolescents, Aboriginal people, people from non-English speaking background and people in aged and dementia care settings.
9. An effective data collection and information system for palliative care.
10. Implementation of accreditation to ensure that appropriate standards in palliative care are achieved by each Area Health Service.
11. A Palliative Care Plan to guide service development and delivery in each Area Health service which ensures that:
    - services are focused on the specific needs of individuals
    - there is 24 hour access to trained palliative care staff. In Areas where there are limited palliative care resources, it is appropriate that systems of triage by generalist staff be explored. 24 hour access may therefore include telephone access by generalist nursing and medical staff to specialist palliative care staff
    - systems are developed that will support partnerships between specialist services and GPs with expertise in palliative care
    - support is available for symptom control and pain management through both generalist service and specialised programs
    - appropriate accommodation is available to meet the needs of palliative care patients. This may be specific inpatient beds or dedicated palliative care beds in a home-like setting. In smaller hospital settings it is appropriate that standards for palliative care beds be identified and implemented when a palliative care patient is admitted

- networks are formalised between palliative care services and inpatient, community based residential aged care facilities and other residential care services as these are essential components of the palliative care service system.
- residential aged care facilities and other forms of permanent or semi-permanent residential care are considered the person's home and the carer role of the staff in these settings recognised
- flexible models of care are explored and implemented according to the available local resources. The role of carers and volunteers should be explored in the process of considering appropriate models of care
- care/services are effectively coordinated and integrated. There are various models that may be used to integrate the delivery of palliative care services for example, case management that is provided under a shared care model involving the individual's GP and staff from specialist palliative care as well as other appropriate services such as dementia care
- the service network provides linkages that promote access to high quality clinical consultation and referral. Although the links will depend on the range of services available in an Area Health Service, the links should ensure appropriate and timely referrals from acute care settings, coordinated discharge planning and support for community staff particularly staff who work in isolation
- a detailed clinical services plan is developed that formalises the networks and linkages from large specialised palliative care services to inpatient beds in other facilities and community based services.

Models of care

There are numerous models and levels of palliative care service delivery across NSW. These models vary due to geographical location, the available resources and historical factors that have over time influenced service funding and service development. For example, in some rural areas close relationships have developed between cancer and palliative care services in order to maximise outcomes from the limited resources available.

The 1996 review, *Palliative Care in Rural Australia*, gives recognition to the diversity of needs in rural communities and the merits of the flexible and consultative models of palliative care that have developed in response to these needs. In particular, the palliative care consultant model provides support to community nursing services, ensures that expertise is available and provides for continuity between the hospital and the community.

Shared care arrangements in which patient information and patient care is shared by service providers such as in arrangements between acute and specialist inpatient services or between specialist public health services and general medical practitioners have also provided for flexible service delivery in both metropolitan and rural areas.

The opportunities for general medical practitioners to participate in shared arrangements have also been broadened through the recent introduction of Medical Benefits Schedule Items for Case Conferencing and Care Planning Information.

An understanding of the palliative care models in place across NSW would provide an important basis for identifying best practice elements in the various models and assist in defining the shape of services or expectations of services from a care delivery perspective. There has however been limited work undertaken to date in terms of mapping and analysing palliative care models.

Assessing quality of service

Although standards have been established for application in general clinical settings for some time, the dimensions and elements of quality in specialist palliative care services indicate that specific standards should be established for palliative care. Establishing palliative care standards and assessing services against the standards would be an important step towards palliative care workers being able to evaluate and account for the quality of their service delivery.

The Commonwealth has given recognition to the need for consistent standards in palliative care across Australia in the National Palliative Care Strategy. The strategy provides for "agreed upon evidence based best practice standards in palliative care service provision and to support and encourage the implementation of those standards".

The Commonwealth standards will not be available in the short term. For this reason, the NSW Health Department acknowledges and supports the Standards for Palliative Care Provision, October 1999, which were developed by Palliative Care Australia (PCA).

The PCA standards resulted from a wide consultation process undertaken with service providers across Australia for the purpose of describing the dimensions and elements of quality in specialist palliative care services. The PCA standards have been designed for use in conjunction with generic quality standards for health care services such as EQuIP (Australia Council on Healthcare Standards) or Quality Management Services (formerly CHASP). Where there are unique aspects of palliative care service delivery that cannot be examined through interpretation of generic standards, they are addressed with a specific palliative care standard.

It is recognised that the PCA standards are most easily applied in specialist palliative care facilities and that work needs to continue on developing standards for community based services. It is also important that performance indicators are developed for each standard so that compliance with standards can be measured.

It is however understood that the standards specified by the PCA are already in place in most health settings even if they are not specifically identified as palliative care standards. For example, while physiotherapists make assessments on the mobility of people receiving palliative care, evidence of the physiotherapist assessments may not at this time be documented with other palliative care service information. As a result the physiotherapists' assessments may not be given recognition as contributing to Standard 1.1: A comprehensive, interdisciplinary assessment of the patient and their family is undertaken to develop a plan of care.

A key step for Areas in addressing this issue may therefore be the development of a single tool for the recording of palliative care data from which evaluation on compliance with standards can be measured.

Measuring service activity and outcomes

Current data

In NSW there are currently three sources of palliative care activity measures:

- Inpatient Statistics Collection (ISC)
- Department of Health Reporting System (DOHRS)
- Australian National Sub-Acute and Non-Acute National Casemix Classification Study (AN-SNAP).

Inpatient activity within the ISC is identified by the service category attached to the episode of care. The analysis of inpatient data has focused on acute activity that is defined by the period of stay and the type of facility. Subsequently, episode of care coding, though likely to be accurate in specialist palliative care units, is less accurate in acute and non-acute facilities.

DOHRS data reports non-inpatient occasions of service provided by hospitals and community health services that report through hospitals. Similar to the ISC data the DOHRS data is constrained and is most likely to accurately record palliative care activity where there are specialist palliative care services.

AN-SNAP measures the phase of care rather than the episode of care and includes data items that capture the specialist palliative care liaison and consultation services that occur in the inpatient setting. The predominant clinical goal of sub and non-acute care is the enhancement or maintenance of quality of life and functional status. This type of care was not adequately described by Australian casemix classifications prior to the development of the AN-SNAP classification[3] which is the national casemix classification for sub-acute and non-acute care. Palliative care is one of the five case types into which AN-SNAP initially separates sub-acute and non-acute patients.

The Department has been implementing AN-SNAP in four phases over four years with implementation commencing on 1 July 1998 in 29 volunteer services. The pilot testing of AN-SNAP has now been completed and AN-SNAP is now being rolled out across NSW as a data collection instrument.

Application of data

Data is important for identifying trends in service delivery. The conversion of population weights and derived growth rates for the purpose of estimating current and projected activity however requires an accurate baseline measure. The measures currently in place are limited in that:

- the reliability of inpatient activity data is poor
- there is no systematic collection of community activity data. This situation is being addressed by AN-SNAP, DOHRS and Community Health Information Data Set
- the current AN-SNAP data set represents only a sample data set and may not be reflective of overall activity
- a significant portion of palliative care activity undertaken as a component of mainstream health service delivery is not identified.

Although no accurate baseline measure of activity exists at this time, the AN-SNAP derived palliative care population weights can be applied to the projected population to indicate growth in demand.

On the basis of projections applying these weights, a 17.3% increase in demand is expected to occur between 1998 and 2006. This compares to an overall population growth of 7%. The relatively higher growth in palliative care reflects high growth rates in the older age groups and the increase in cancer survival rates.

Unlike acute activity projections, this projection does not incorporate changing trends in service delivery. There is insufficient historical palliative care activity data to determine the changing pattern of palliative care service provision.

Future directions in the measurement of service activity and outcomes

There are a number of areas relating to the measurement of palliative care service activity in which it would be appropriate to focus initiatives in the future. In particular future data developments should explore options for reflecting the full continuum of care required by people who are dying.

As a significant proportion of ambulatory palliative care services are provided by non-hospital based health care workers, it is important that future initiatives explore options for capturing accurate data on the range of community based services used by these patients including general practitioner services.

While AN-SNAP has limitations as a data collection instrument for example, it provides no measures on outcomes and does not recognise the differences between rural and metropolitan settings, AN-SNAP is at this time likely to provide the most accurate measure of inpatient and community based palliative care occasions of service.

The data generated from AN-SNAP also provides a basis for an improved understanding of the activity of palliative care units and is therefore a foundation for developing meaningful performance indicators, improved accountability and benchmarking of services.

The implementation of AN-SNAP across health services statewide is therefore supported by the NSW Health Department as an important step forward for palliative care.

Service utilisation

As discussed in the previous sections, the main source of reliable data on palliative care is from the specialist inpatient services.

In 1998/99 there were a total of 7,886 coded palliative care separations, 38% of which were from four hospitals, as described in Table 1.

Appendix 6 provides additional data on palliative care service utilisation and expenditure on services.

The concentration of palliative care activity where specialist inpatient services are located is in metropolitan Areas. Although all Area Health Services provide inpatient care where appropriate for people requiring palliative care, not all Areas directly allocate a specific number of palliative care beds. For this reason it would appear that the provision of a predetermined number of palliative care beds for a set population is not the most efficient indicator of an effective palliative care service. A range of factors therefore need to be considered when determining a measurement tool for the clinical effectiveness of palliative care services for example, patient awareness, utilisation of services.

Hospital	Area of Hospital	Total	% total palliative care separations	Cum. % separations
Calvary	South Eastern Sydney	1,241	15.7%	15.7%
Sacred Heart	South Eastern Sydney	774	9.8%	25.6%
Neringah	Northern Sydney	488	6.2%	31.7%
Newcastle Mater	Hunter	474	6.0%	37.8%

Source: NSW Health Services Comparison Data Book 1998/1999

Table 1. Number and cumulative percent of palliative care separations, identified by Inpatient Statistics Collection (ISC) service category (1998/99)

Palliative care funding consideration

Allocations from the NSW Health Department to Area Health Services

There are three sources of funding for palliative care services in NSW:

- dedicated palliative care funding
- funding through the Rehabilitation and Extended Care Program
- a component of HIV/AIDS funding.

The Commonwealth Government provides some dedicated funding for palliative care through the Australian Health Care Agreements (AHCA). Although the level of Commonwealth funding has dropped since 1997/98, the overall funds available to support the NSW palliative care service infrastructure have been maintained as NSW supplements the Commonwealth monies. Palliative care allocations from the Commonwealth will continue until at least 2002/03 when the current AHCA ends.

Funding made available to Area Health Services through the Rehabilitation and Extended Care Program includes a component for palliative care. For more information on the expenditure of the Rehabilitation and Extended Care Program funding refer to Appendix 6.

Funding allocations from the Rehabilitation and Extended Care Program are guided by the NSW Resource Distribution Formula (RDF) which is a population based funding formula built up by considering health needs relevant to particular types of services. A range of factors relating to palliative care are included in the build up of the RDF. These factors are:

- the age/sex profile for each Area Health Service using weights from the National Sub and Non Acute Patient (AN-SNAP) study
- a need index based on Cancer Standardised Mortality Ratios and
- a substitutable private sector activity factor to reflect use of private hospitals for palliative care services.

Appendix 4 illustrates how the various factors in the formula affect the target share of funding across Area Health Services. It is however evident that the age/sex weights require review to reflect paediatric care as the current weights do not recognise under 20 year olds (see Appendix 3). There will also, at times, be a need for people to seek palliative care outside their local Area Health Service. In particular, the inter-area flows that occur through children, people from non-English speaking backgrounds and HIV/AIDS patients travelling to appropriate services should be anticipated and planned for.

A component of funding for HIV/AIDS services also relates to palliative care. Funding allocations made from the NSW AIDS Program to Area Health Services are intended as a contribution toward the cost of HIV/AIDS service provision, and are deployed to palliative care on a needs basis.

As the palliative care funds distributed to Area Health Services through the Rehabilitation and Extended Care Program are not specifically earmarked for palliative care services, the distribution of funding to the range of palliative care services will be dependent on local priorities and the budget decisions made by Area Health Services.

In effect, each Area Health Service including the Corrections Health Service and the Children's Hospital at Westmead has responsibility for determining the proportion of their available Rehabilitation and Extended Care Program budget that should be invested in specific programs such as palliative care to achieve health improvement priorities and to meet the health needs of their local population.

Future funding directions

As the goals of palliative care are broad and include quality of life support services, factors other than diagnosis are likely to explain the costs in care. The data derived from AN-SNAP is on the period of treatment and can include palliative care in both community and hospital settings. It will therefore provide a more accurate measure of palliative care services than has been possible to date, a funding model based on AN-SNAP data will in the future provide an improved basis for the funding of palliative care services.

As AN-SNAP has not been fully rolled out across NSW the majority of services involved in the pilot phase of AN-SNAP have been designated inpatient services. It is therefore impractical at this time to use a funding formula for palliative care based on AN-SNAP classes. The NSW Health Department does however propose to use AN-SNAP as a basis for funding palliative care services from 2003.

In the interim, two funding alternatives for inpatient services are available:

- a per bed-day approach for all palliative care patients
- a per bed-day rate adjusted to reflect the patients within the 11 AN-SNAP admitted patient classes.

While each alternative has its limitations, they are the preferred options for funding palliative care services until NSW is able to progress a funding formula based on AN-SNAP.

Future directions for palliative care in NSW

While the development of the *NSW Palliative Care Framework* has been an important first step in the planning of palliative care services on a statewide basis, work needs to continue on refining various issues, for example, funding and measuring service activity and outcomes.

It is also deemed important that the processes and practices within the system be evaluated over the next three years. The lessons learnt from the implementation of the Framework together with the data generated from AN-SNAP will provide an informed basis upon which future documents can be developed.

During the consultation process in developing this document a number of tasks have been identified for achievement by Area Health Services and the NSW Health Department during the life of this Framework.

Directions for Area Health Services

1. The planning of palliative care services and the identification of linkages between palliative care and other relevant services is considered essential for the achievement of effective outcomes in service delivery.

   As a step intended to support a planning process state-wide, each Area Health Service across NSW is required to submit for endorsement to the Department by the 30 December 2001 a three year Area Palliative Care Services Plan that identifies the palliative care resources available within the locality and is based on:

   - estimates of the population's future service requirements
   - a service delivery model which recognises individual needs and the imperative of an effective interface by palliative care services with other clinical services
   - an analysis of the service and funding reconfigurations required to provide resources to meet current and the projected palliative care needs of the population
   - clear lines of communication on planned service delivery from service management to individual service provider.

2. Although it is recognised that, at this time, some Area Health Services would have difficulty in meeting all key elements for effective palliative care, planning should be initiated to bridge gaps in the provision of the elements.

   - The Palliative Care Services Plan of each Area Health Service must identify how local services comply with the key elements for effective palliative care. Where services do not include all key elements, Areas should identify strategies and a timeframe for bridging existing gaps in the Plan.

3. It is widely acknowledged that specific standards for palliative care service provision require recognition and implementation.

   - The Palliative Care Services Plan of each Area Health Service must identify strategies for evaluating service compliance with Palliative Care Australia's Standards for Palliative Care Provision. When gaps exist in an Area's ability to comply with the Standards, strategies and a time frame for addressing gaps should be identified in the Plan.

4. Given the recognised barriers to service access by people living in rural and remote areas, access by people living in these areas to specialised services needs to be improved.
   - Where gaps in access to the full range of specialist medical, nursing and allied health palliative care services exist, Area Health Services must negotiate and identify in their Palliative Care Services Plan formal linkages with specialist services. As an outcome of formal linkages being established, gaps in service delivery may be bridged by a range of mechanisms such as telephone consultation and Telehealth.
   - In view of the limitations of service delivery, the spread of the population and the costs in some rural and remote areas, the Cancer Care Model may be considered the most effective model for service delivery. Where oncology services and palliative care services are linked, specific planning must be undertaken and protocols developed to ensure a balance of service delivery and access to treatment, care and support by people requiring palliative care but who do not have a cancer-related diagnosis.
5. The *National Palliative Care Strategy* identifies a range of strategies to be implemented at a national level to achieve greater community awareness of palliative care, a higher level of knowledge and skills for families, carers and community groups to support people requiring palliative care, and for promoting professional awareness of palliative care as an integral part of the health care system.
   - All palliative care services will be required to support relevant Commonwealth initiatives that focus on palliative care information and training. In addition Area Health Services must identify and support opportunities for providing:
     - information on local palliative care services
     - training that promotes quality support by carers and family for people with a terminal illness
     - training to promote an understanding by health professionals of palliative care, a responsiveness to the clinical and social needs of people with a terminal illness and appropriate referral to palliative care.
6. The specialist palliative care workforce must be responsive to the palliative care needs of the populations they serve.
   - Area Health Services support, where negotiated with individual staff, the interchange of staff between metropolitan and rural settings to promote linkages between metropolitan and rural services and as a professional development opportunity.
   - Area Health Services must regularly review their models of palliative care service delivery in the context of local demand for services. Where trends require that services are provided in a different way for example, from inpatient to community based service delivery, or the location of services provided, the proposed changes should be identified in the service planning process. It is essential that direct service providers are consulted with and involved in any developments.
   - While it is recognised that a high level skill base already exists among the palliative care workforce across NSW, Area Health Services must support access by palliative care staff to ongoing professional development.
   - Strategies for providing information, training and professional development must be identified in the Palliative Care Services Plan of each Area.

Directions for the NSW Health Department

7. The National Palliative Care Strategy documents the Commonwealth's intention to implement strategies targeting the following:

– the provision of information that will increase awareness of the community and professionals

– the provision of training that will increase the skills of carers and professionals

– development of standards of care and best practice

– accountability and reporting.

As the strategies of the National Palliative Care Strategy will have statewide implications, the NSW Health Department has a responsibility to advocate for:

- the resources to address the palliative care information and training needs of the community, carers and health professionals including resources that will address the information and training needs of minority groups and in specialised settings for example, specific cultural groups, Corrections Health staff and allied health workers from the Department of Corrective Services
- a National Palliative Care Data Set that is consistent with data developments within NSW and the resources to provided data at the local level including mobile data resources, training and technical support required in rural areas
- service quality benchmarks appropriate to NSW palliative care services
- performance indicators that focus on processes and outcomes rather than inputs.

8. Consistent with the *National Palliative Care Strategy,* the NSW Health Department has a role in promoting partnerships through:

- Consulting and working with Area Health Services and other key stake holders on policy development
- Allocating resources in ways, where feasible, that promote partnerships
- Promoting networks between rural and metropolitan palliative care services in the context of available funding in future planning documents.

9. There are a number of issues associated with the geographical location of some rural and remote areas that require further exploration by the NSW Health Department. These include:

- coordination of care with general practitioners including the care provided at district hospitals given that general practitioners are key service providers in rural areas
- minimum service requirements for implementation during a palliative care inpatient admission in locations where it is not cost effective to maintain specific palliative care units or other forms of dedicated palliative care inpatient services
- expanded role of palliative care nurses in some community settings in the context of the nurse practitioner program.

10. As it is widely recognised that accurate data is necessary to support planning of appropriate palliative care services, to achieve accountability for these services and an equitable funding model the following actions are required:
    - the NSW Health Department continue to implement AN-SNAP for the purpose of strengthening data collection on palliative care service provision
    - the NSW Health Department investigate the opportunities for undertaking a costing study that would evaluate differences in service costs between rural and metropolitan settings
    - the NSW Health Department seek advice on appropriate palliative care outcomes and how data collection measures on palliative care outcomes can be developed in the future
    - the NSW Health Department implement a funding model based on AN-SNAP from 2003
    - the NSW Health Department review the age weights in the existing Resource Distribution Formula to promote equitable funding for paediatric palliative care services.
11. In the context of increasing demands on palliative care services and pressures on the health system to provide high levels of care, it is considered essential that long term planning and flexible service delivery be supported and that steps be initiated for establishing best practice in palliative care service delivery including the following:
    - the NSW Health Department explore opportunities for mapping and assessing the models of palliative care in place across NSW
    - the NSW Health Department consult on the development of a comprehensive NSW Palliative Care Service Plan with the intention of implementing the Plan in 2004 when the time frame for the Palliative Care Services Framework expires.

It is recognised that the advice provided by Area Health Services, individual professionals and representative community organisations during the development of this document has been vital to the completion of a *NSW Palliative Care Framework*.

The NSW Health Department is committed to progressing the document's strategies over the next three years and continuing to consult with the range of stakeholders. Broad initiatives such as the NSW Action Plan for Health will have a significant impact on the health system over future years including palliative care service delivery. It is therefore important that palliative care continues to be given specific recognition as a key element in the health system.

It is envisaged that the *NSW Palliative Care Framework* will progress palliative care service development across NSW and the evaluation of outcomes will provide directions for the future and inform future palliative care policy documents.

Appendix I

References

Commonwealth Department of Health and Family Services, *Report to the Palliative Care Program Review Stage One: A Report by Kasap & Associates Pty Ltd to the Palliative Care Steering Committee* Commonwealth of Australia, 1997

Commonwealth Department of Health and Family Services, *Palliative Care in Rural Australia: A Research Project of the National Palliative Care Program by Sach & Associates*, Commonwealth of Australia, 1996

Commonwealth Department of Health and Aged Care, *National Palliative Care Strategy*, 2000

NSW Health Council, *A Better Health System for NSW*, 2000

NSW Health Department, *Strategic Directions for Health 2000-2005, Better Health Good Health Care*, 2000

NSW Health Department, *Case Conferencing, Care Planning: Information on the new MBS items to facilitate the participation of General Practitioners,* Information Bulletin No 2000/7.

NSW Health Department,*Cancer Care Model for NSW : Final Report of the Cancer Care Model Working Party to the Optimising Cancer Management Group*, December 1997

NSW Health Department, *Health Outcomes for People Who Use Palliative Care Services: A study by Devery, K., Lennie, I., & Cooney, N* (Funded by the NSW Health Outcomes Project), 1996

NSW Health Department, *Report of the NSW Health Palliative Care Working Party*, 1993

NSW Health Department, *Guidelines for the Development of Palliative Care Services in NSW*, 1985

NSW Ministerial Advisory Committee on Health Services in Smaller Towns, *A Framework for Change*, 2000

Palliative Care Australia, *Standards for Palliative Care Provision*, October 1999, Third edition

Notes

1 Palliative Care Australia: Standards for Palliative Care Provision – October 1999

2 Commonwealth Department of Health and Aged Care, National Palliative Care Strategy (October 2000)

3 For detailed definitions of case types refer to the NSW AN-SNAP Clinical Training Handbook (NSW Health & Centre for Health Services Development, University of Wollongong, 1999).

Appendix 2

Further information

Listed below are some useful sources of information regarding palliative care:

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care in Australia, and provides a number of services representing the views of those working toward the relief of pain and suffering of those who are dying. A range of information is available on their Website, including a National Directory of Palliative Care Services.

Palliative Care Australia
PO Box 55
Yarralumla ACT 2600
Tel. (02) 6232 4433
Fax.(02) 6232 4434
Email. pcain@pallcare.org.au
Website. www.pallcare.org.au

Palliative Care Association of NSW (PCANSW)

PCANSW is the peak advisory body for palliative care in NSW. The Association aims to increase the awareness of palliative care throughout the community and health industry and provide an avenue for communication and networking of palliative care services in NSW. The Association provides education for the public, palliative care professionals and other health workers.

Palliative Care Association of NSW
PO Box 572
Kings Cross NSW 1340
Tel. (02) 9334 1891
Fax. (02) 9326 9328
Email. nsw.palliativecare@nswcc.org.au

Palliative Care Council of South Australia Inc

The Palliative Council of South Australia is a statewide, community based representative organisation for palliative care in South Australia that has recently completed a multicultural project, which included consultation, production of brochures for some major cultural groups, development of multicultural guidelines (available on Website).

Palliative Care Council of South Australia Inc
202 Greenhill Road
Eastwood SA 5063
Tel. (08) 8291 4137
Fax. (08) 8291 4122
Email. pcare@adelaide.on.net
Website. www.pallcare.asn.au

Australia Council on HealthCare Standards (ACHS)

Information about becoming accredited under EQuIP can be sought from the ACHS.

Australia Council on Health Care Standards
5th Floor
70 Phillip St
Sydney NSW 2001
Tel. (02) 9251 7400
Fax.(02) 9251 7477
Email. achs@ilanet.sinsw.gov.au

Quality Management Services (QMS - formerly CHASP)

Information about becoming accredited under QMS can be sought from QMS.

Quality Management Services
303a Smail St
Ultimo NSW 2000
Tel. (02) 9212 1433
Fax. (02) 9212 1477

Growth House

An international Website providing a broad range of information and research on palliative care services.

Website. www.growthhouse.org

Appendix 3

Age/Sex weights for palliative care

Age Group	Male	Female
0-4	-	-
5-9	-	-
10-14	-	-
15-19	-	-
20-24	0.04	0.04
25-29	0.05	0.05
30-34	0.12	0.17
35-39	0.21	0.29
40-44	0.27	0.37
45-49	0.62	0.86
50-54	0.82	1.13
55-59	1.75	1.75
60-64	2.61	1.96
65-69	4.52	3.39
70-74	6.64	4.98
75-79	6.95	5.21
80-84	9.95	7.47
85+	10.26	7.69

Appendix 4

Palliative care components of RDF

	Estimated Resident Population December 1999	Age/Sex Weighted Population	Age/Sex/Need Weighted Population	Age/Sex/Need Weighted Population Adjusted for Use of Private Hospitals	Target Share of Resources
100 Central Sydney	491,475	474,801	506,894	517,349	8.0%
105 Northern Sydney	772,114	842,947	749,937	730,481	11.3%
120 Western Sydney	679,555	543,312	563,742	574,028	8.9%
125 Wentworth	315,546	234,012	237,198	238,323	3.7%
130 South West Sydney	778,826	610,583	626,219	636,060	9.8%
135 Central coast	292,749	362,990	377,728	378,710	5.8%
140 Hunter	540,614	572,525	595,771	608,936	9.4%
145 Illawarra	351,884	377,843	389,785	371,137	5.7%
155 South Eastern Sydney	773,565	794,545	818,069	828,902	12.8%
400 Northern Rivers	269,598	324,699	292,118	244,616	3.8%
410 Mid North Coast	267,472	351,190	340,173	347,732	5.4%
420 New England	174,900	183,734	183,664	188,012	2.9%
430 Macquarie	104,674	104,917	104,667	107,145	1.7%
440 Mid Western	168,091	168,887	169,667	173,448	2.7%
450 Far west	47,398	49,940	50,819	52,022	0.8%
460 Greater Murray	259,351	269,528	268,617	274,932	4.2%
470 Southern NSW	186,889	208,248	199,634	202,868	3.1%
Total	6,474,701	6,474,701	6,474,701	6,474,701	100.0%

Appendix 5

AN-SNAP classes for palliative care

Class	Episode Type	Description
101	Overnight	Stable, RUG 4
102	Overnight	Stable, RUG 5-17
103	Overnight	Stable, RUG 18
104	Overnight	Unstable, RUG 4-17
105	Overnight	Unstable, RUG 18
106	Overnight	Deteriorating, RUG 4-17
107	Overnight	Deteriorating, RUG 18, age <=71
108	Overnight	Deteriorating, RUG 18, age >=72
109	Overnight	Terminal, RUG 4-16
110	Overnight	Terminal, RUG 17-18
111	Overnight	Bereavement
151	All ambulatory	Medical only
152	All ambulatory	Therapies only
153	All ambulatory	Stable, Multidisciplinary
154	All ambulatory	Stable, Nursing only, severity <= 10, RUG 4, age >=67
155	All ambulatory	Stable, Nursing only, severity <= 10, RUG 4, age <=66
156	All ambulatory	Stable, Nursing only, severity <= 10, RUG 5-18
157	All ambulatory	Stable, Nursing only, severity >= 11
158	All ambulatory	Unstable, Multidisciplinary, RUG 4, severity <= 11
159	All ambulatory	Unstable, Multidisciplinary, RUG 4, severity >= 12
160	All ambulatory	Unstable, Multidisciplinary, RUG 5-18
161	All ambulatory	Unstable, Nursing only, RUG <= 14, age >= 60
162	All ambulatory	Unstable, Nursing only, RUG <= 14, age <= 59
163	All ambulatory	Unstable, Nursing only, RUG >= 15
164	All ambulatory	Deteriorating, Multidisciplinary, severity <= 10
165	All ambulatory	Deteriorating, Multidisciplinary, severity >= 11, RUG <= 10
166	All ambulatory	Deteriorating, Multidisciplinary, severity >= 11, RUG >= 11
167	All ambulatory	Deteriorating, Nursing only, RUG 4
168	All ambulatory	Deteriorating, Nursing only, RUG 5-18
169	All ambulatory	Terminal, Multidisciplinary
170	All ambulatory	Terminal, Nursing only
171	All ambulatory	Bereavement, age >= 45
172	All ambulatory	Bereavement, age <= 44

Appendix 6

Palliative care expenditure

In 1997 a survey of all Area Health Services was undertaken, revealing that 14.9% of expenditure under the Rehabilitation and Extended Care Program related to palliative care services. This data yields the following estimates of expenditures across the four years from 1996/97 to 1999/00:

	Rehabilitation & Extended Care Program: Expenses	Estimated Palliative Care share	Estimated Palliative Care Expenses	Commonwealth funding
	$m	%	$m	$m
1996/97	663.1	14.9	99	10.5
1997/98	654.8	14.9	98	11.3
1998/99	775.9	14.9	116	9.6
1999/00	797.9	14.9	119	9.8

Table 2. Palliative Care/Commonwealth components of Rehabilitation & Extended Care Program

The following is an estimate of the break up of the $116 million spent on palliative care in NSW during 1998/99 as identified in Table 2:

Facility	$m
Hospices	32.3
Non Acute Facilities with a substantial Palliative Care role	16.3
Other Facilities: Inpatient Services	15.6
Other Facilities: Community and Ambulatory Services	51.8
Total for 1998/99	**116.0**

Table 3. NSW Palliative Care Expenditure 1998/99

The breakdown of the $32.3 million expended in hospices as identified in Table 3 was reported to the NSW Department of Health as follows:

Facility	Total expenses $m
Calvary	15.6
Neringah Home of Peace	4.8
Sacred Heart Hospice	11.9
Total	**32.3**

Table 4. NSW Hospice Expenditure 1998/99

Expenses on palliative care services within non acute facilities that have a significant palliative care role, are estimated to have been $16.3 million in 1998/99:

	Total Bed Days	Palliative Care Bed Days	% of Bed days	Total Expenditure $m	Estimated Palliative Care expenditure $m
Braeside Public	20,625	6,333	31%	10.7	3.3
David Berry	6,166	2,163	35%	3.1	1.1
Greenwich Home of Peace	20,279	4,810	24%	10.4	2.5
Lottie Stewart	19,070	3,214	17%	13.0	2.2
Mercy Care Centre Young	11,557	959	8%	9.0	0.8
Mercy Hospital Albury	13,445	1,719	13%	6.2	0.8
St John of God Goulburn	12,229	1,235	10%	7.0	0.7
St Joseph's Auburn	21,824	7,040	32%	14.5	4.7
Total	**125,195**	**27,473**	**22%**	**74.1**	**16.3**

Table 5. Palliative Care Expenditure by facilities with major palliative care role
Source. NSW Health Service Comparison Data Book 1998/99

A further 38,449 bed days were reported for other facilities in 1998/99. At an estimated cost of $405 per bed day (NSW Cost of Care Standards 2000/2001), this represents total expenses of $15.6 million in these facilities on admitted patients. It is estimated that community based and ambulatory services accounted for a further $51.8 million in 1998/99.