South Western Sydney Area Health Service

A Strategic Plan for Palliative Care Services

2001 – 2004

Version 2.1
February 2002

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EXECUTIVE SUMMARY

This Plan, *"A Strategic Plan for Palliative Care Services 2001-2004"* aims to provide a clear direction for palliative care service provision in South Western Sydney Area Health Service (SWSAHS). This plan follows comprehensive consultation throughout SWSAHS undertaken as a part of the Gleeson Health Care Consulting *"Report of Review of Palliative Care Services in South Western Sydney Area Health Service"*.

The Gleeson report was published in 2001 and highlighted the difficulties in effecting changes across all care settings and Sectors in SWSAHS. The Review identified the following issues facing palliative care service delivery in the Area

- Increasing activity with no change in resources
- Inadequate medical, nursing and allied health staffing
- Quality and coordination problems across Sector Health Services and care settings
- The absence of an appropriate structure to facilitate the implementation of both Commonwealth and NSW Health guidelines uniformly across the Area.

Readers are referred to the Gleeson report for detail on the findings of the review and the recommendations.

At the same time the NSW Department of Health has released the *"New South Wales Palliative Care Framework, A guide for the provision of palliative care in NSW"* which details a number of areas where Area Health Services need to show compliance with, or progress towards compliance. Among these areas is the adoption by NSW Health of the Palliative Care Australia *"Standards for Palliative Care Provision"*.

The significant enhancement to the Palliative Care Service budget, and the funding for Priority Health Care Programs has enabled considerable expansion to the Palliative Care Service in SWS. Additional medical and nursing staff, an Area Palliative Care Coordinator position and the introduction of 24 hours access to specialist palliative care advice will contribute to achieving the aim of timely, seamless service delivery for SWS residents needing palliative care.

The proposed model for Palliative Care Services in SWS, as illustrated on page 16 of the plan, places the patient at the centre of care delivery. This emphasises that 'the care should follow the patient'. That is, as the patient moves between care settings access to specialist palliative care is always available. While it is acknowledged there are varying operational practices in Sectors the performance goal at this time is to achieve timely access for patients to palliative care services and the achievement of PCA standards. Over time the proposed strategies will assist in attaining more consistent standardisation of practices and treatments.

Braeside Hospital at Fairfield, owned and operated by Hope Health Care, includes a 20 bed inpatient palliative care unit, a Day Hospital, Outpatient Palliative Care Clinic and the provision of consultancy services to other hospitals in the Area. The opening of the new Palliative Care Inpatient Unit at Camden Hospital with 10 designated palliative care beds is anticipated to greatly improve access to services for residents in the southern Sectors of SWS.

An acknowledged gap in SWS is facilities for patients requiring long term care with a higher level of dependency than living in their own home can provide. Strategies have been developed to review and assess the needs of the SWS population for long term care and to seek out opportunities to develop solutions.

In order to facilitate better management of the dying phase SWSAHS needs to ensure timely identification of those who are actually dying, treat distressing symptoms and syndromes in the 'actually dying' phase, and allow people to die in the place of their choice. The importance of partnerships with primary and specialist, and community based health care providers is recognised and the plan contains strategies to develop partnerships where gaps have been identified, and to strengthen those partnerships already in place.

Cicely Saunders, credited with founding in the UK the modern hospice movement attributes the wish of one of her early patients as being the catalyst for her impetus to found the Hospice Movement in the UK – "I only want what is in your mind and what is in your heart".

There are a number of areas outlined in the plan where service development is still required. This service development will ensure the needs of all patients requiring palliative care are being met, as well as meeting the imperative of compliance with the Palliative Care Australia Standards. The support needs of carers, family and friends as well as staff working with palliative care patients cannot be overlooked and strategies have been developed to ensure those caring for and working with palliative care patients have access to a full range of psycho-social resources to meet these needs.

This plan will inform the business plans of the Sector based Palliative Care teams and these business plans will be developed to reflect local needs and will be in conjunction with Sector business plans.

All strategies in the plan have been cross-referenced in the text and appear in brackets in ***Bold Italics***.

Policy and Strategic Direction

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment."[i]

The above definition of palliative care has been suggested by the World Health Organisation and is an inclusive description of the broad range of care needs of palliative care patients.

Commonwealth

> *"Not to see suffering as at least part of our medical responsibility risks turning the emerging discipline of Palliative Medicine into a reductionist technicist specialty of symptom management rather than whole person care"*
> Prof. David Barnard
> Palliative Care and Medical Ethics, University of Pittsburgh

The Commonwealth Department Of Health and Aged Care has developed a National Palliative Care Strategy. *A National Framework for Palliative Care Service Development* was released in October 2000.

The national Framework confirms the Government's commitment to develop and implement consistent policies, strategies and services in Australia. The strategy is founded on the premise that such care must form an integral part of a comprehensive health care system that supports people at all stages of life.

It defines palliative care; those who should receive palliative care; what a palliative care team should consist of; coordination of palliative care across all care settings; those who might require special consideration when forming strategies.

The three main goals are as follows.

Goal 1 - Awareness and Understanding

The strategies in relation to achieving goal one aim to improve community and professional awareness about the dying process, what palliative care is and what can be provided. Its other major feature is its aim to improve professional commitment in all Area Health Services to Palliative Care. This is about improving attitudes and approaches towards death and dying amongst society and health care providers.

Goal 2 - Quality and Effectiveness

Strategies in relation to goal two involve:

- Development of national minimum standards based on existing standards such as those from Palliative Care Australia (PCA);
- Evaluating all Australian palliative care services against these standards within a given timeframe;
- Establishing efficient administrative and resource allocation structures that support the provision of best practice palliative care and an integrated service system; and

- Developing nationally consistent reporting on palliative care provision in both public and private sectors across all service delivery settings.

A key issue is the proposal to develop and promote resource allocation arrangements that provide incentives to deliver care. The aim is that this care is integrated within and across all settings, with continuity of professional carers, and flexibility to provide care in the setting that best meets the changing needs of the person who is dying, with easy movement between settings as required.

Goal 3 - Partnerships in Care

Partnerships are considered at a number of levels. These include:

- At the individual level;
- Partnerships in service planning and delivery;
- Promoting the establishment of administrative arrangements that promote and support the delivery of integrated and accessible palliative care services through resource allocation, accountability and reporting arrangements and collaboration between central administration and service providers;
- Developing and promoting the provision of specialist palliative care consultant service support to primary and specialist health care providers involved in care for people who are dying regardless of diagnosis, setting or geographical location;
- Establishing effective and coordinated information and referral services for palliative care;
- Developing service models and service partnerships that achieve coordinated care for people who are dying and their families and promote the implementation of such models by specialist palliative care providers relevant to each region and accessible to clients, providers and the general community.

State

NSW Health has developed a Palliative Care Service Framework - *A Guide for the Provision of Palliative Care in NSW Area Health Services*. The final document was released in August 2000.

This document is consistent with Commonwealth directions and affirms that NSW Health is committed to the provision of services that maximise the quality of life for people with advanced progressive disease or terminal illness. It is highlighted that this can only be done when palliative care is provided in an integrated and coordinated fashion across the four care settings. These include inpatient palliative care units, general inpatient services, community and outpatient settings.

In relation to the assessment of quality NSW Health has accepted Palliative Care of Australia (PCA) standards as National Standards. SNAP is recommended in the NSW Health Palliative Care Framework as an accepted classification system ***(4.6)***.

The important implications to Area Health Services are:

1. That all NSW Area Health Services identify strategies for evaluating service compliance with Palliative Care Australia's Standards for Palliative Care Provision that include a timeframe for addressing gaps ***(1.2)***.

2. That a funding model based on AN-SNAP be developed and implemented by 2003 for designated AN-SNAP inpatient units.

In summary this means that Area Health Services will need to demonstrate that an integrated palliative care service is provided, or strategies and timeframes identified to achieve this. Also that there are the tools in place and the data available to attract the appropriate funding.

Local

Gleeson Health Care consulting was commissioned by the Area Palliative Care Service (APCS) to undertake a review of services in SWSAHS and to make recommendations. The final draft report was accepted by the Steering Committee in October 2000. The review highlighted the difficulties in instigating changes across all care settings and Sectors in SWSAHS.

Overall, the recommendations of the Review are consistent with both Commonwealth and State directions in palliative care. The *SWSAHS Strategic Plan for Palliative Care Services 2001-2004* provides clear direction for the provision of services to meet the needs of the SWS population for the next 4 years. The strategies and implementation plan have been developed from the 53 recommendations arising from the review which have also contributed to the formation of service goals and objectives.

The plan is consistent with achieving the State and Area Health Service purpose of **Better Health, Good Health Care**.

The goals of NSW Health, which have been adopted by SWSAHS are
- **Healthier People**
- **Fairer Access**
- **Quality Health Care**
- **Better Value**

The planning principles of SWSAHS are
1. **Equity**
2. **Efficiency**
3. **Effectiveness**
4. **Acceptability**

As well as these four objectives SWSAHS also embraces **safety** in the workplace and **community participation** in the development and planning of services.

To achieve the purpose of **Better Health, Good Health Care** SWSAHS has identified these 7 key challenges:

1. Working with our community and staff to develop a shared sense of responsibility and direction
2. Working in partnership with other agencies to improve health
3. Ensuring that people in SWS access health services according to need
4. Making the best use of and fairly allocating existing and incoming resources
5. Developing effective and efficient health services which focus on improved health outcomes

6. Attracting, developing and retaining the best staff
7. Becoming a learning and teaching organisation

The SWSAHS key challenges have guided the development of this plan and have influenced the strategies and implementation plan that are presented later in the document.

The plan's major objective is to address the implementation planning for the organisation and delivery of palliative care services in SWS to provide optimal outcomes for the terminally ill.

Background

The review of palliative care services was an initiative of South Western Palliative Care Service who were seeking to evaluate current service provision, to identify existing gaps or deficits in these services and thereby to have the basis for sound planning for future service development. The review process was under the auspices of a Steering Committee who were representative of the major palliative care service providers in SWS.

> *"Palliative Medicine is planned care, not crisis intervention"* Oxford Textbook of Palliative Medicine

Hope Healthcare own and operate under a management contract with SWSAHS Braeside Hospital. Braeside Hospital includes a 20 bed inpatient palliative care unit, a Day Hospital, an Outpatient Palliative Care Clinic and also provide consultant services to other hospitals in the area and in the community. Camden Hospital will have 10 designated palliative care beds when opened.

The demand for palliative care in SWS has increased over the last 3 years in terms of referrals, admissions and consultations. The review found that, when benchmarked against palliative care services in other Area Health Services, SWSAHS is significantly under-resourced. The benchmarking information from the Gleeson report has been reproduced in the Appendices. (See Table 8 at Appendix III). The available resources to date have been stretched to capacity in order to meet existing demand and significant enhancements to the service have been made with the 2000-2003 budget allocation ***(2.1)***.

The NSW Health Priority Health Care Program (PHCP) has also funded a palliative care proposal to provide access to 24 hour specialist palliative care advice through the use of 1300 telephone numbers ***(2.7)***. A Palliative Care Coordinator position has also been jointly funded through budget enhancement and PHCP ***(2.12)***. This program will include the establishment of formalised links with Emergency Departments with the aim of avoiding unnecessary acute admissions. ***(3.12)***

Geographic and Population Profile

Geography

South West Sydney (SWS) comprises the seven local government areas of Bankstown, Camden, Campbelltown, Fairfield, Liverpool, Wingecarribee and Wollondilly and covers an area of 6,237km^2 with a total population of 769,243.

Settlement varies from quite dense suburban residential development in Bankstown to scattered rural townships in Wingecarribee and Wollondilly. Parts of the Area are quite geographically isolated, particularly in Camden, Wingecarribee and Wollondilly and the western parts of Fairfield and Liverpool.

Population

1996 ABS census data indicates that the intercensal population growth in SWS (8.4%) was higher than that for the whole of NSW (5.4%), particularly in Camden and Liverpool. Based on population numbers this makes SWSAHS the second largest health area in NSW. Population projections indicate that by 2006 it will be the biggest health area in NSW (population based) with 840,680 people growing to 879,170 people by 2011. Currently 28.5% of the population are from NESB (compared to 15.7% in NSW) and 1.2% are Aboriginal or Torres Strait Islander people.

The population projections for South Western Sydney indicate a growth of 25% between 1996 and 2016. As well as overall population growth, the proportion of elderly people in SWSAHS is projected to increase from 9.1% to 12.6% of the total population. The growth in the number of people from culturally and linguistically diverse backgrounds indicates that SWS is an increasingly multicultural region.

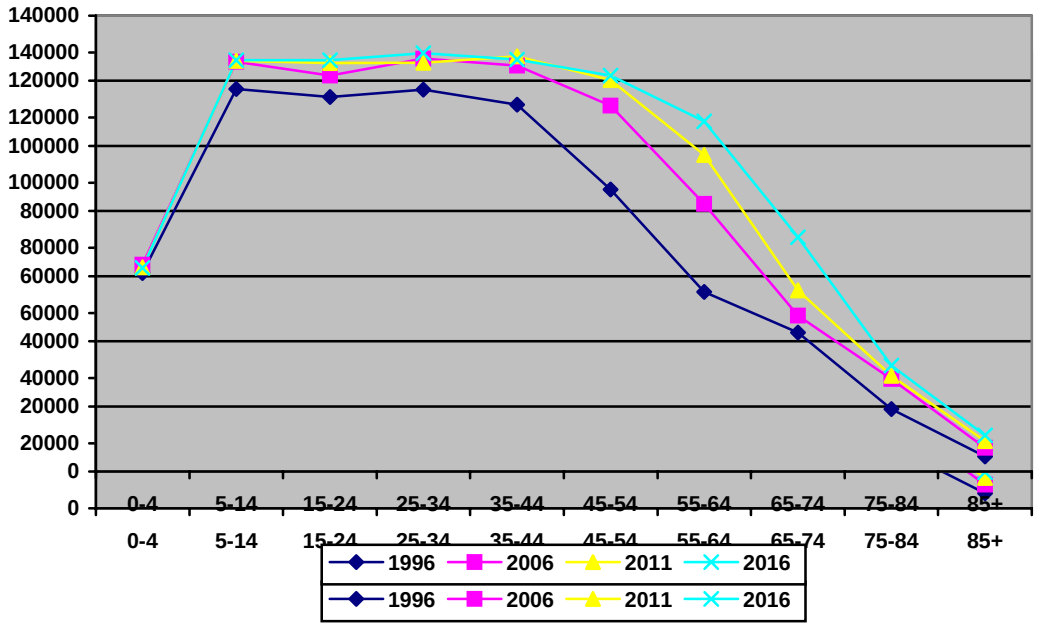
SWS Projected Population Growth

Table 1 - Population projections by SWS LGA (total population)

LGA	1998*	2006	2011	2016
Bankstown	167,839	169,400	169,490	169,490
Camden	37,767	58,200	68,040	77,490
Campbelltown	149,489	156,840	158,420	159,530
Fairfield	190,920	193,680	193,460	192,600
Liverpool	137,066	176,600	197,710	217,110
Wingecarribee	39,346	45,070	47,930	51,240
Wollondilly	35,489	40,890	44,120	47,580
Total SWS	757,916	840,680	879,170	915,040

**1998 Estimated resident population*
Source: Department of Health Population Projections for NSW Area Health Services March 2000

Figure 1 - Population projections by age group



Source: Department of Health Population Projections for NSW Area Health Services March 2000

As demonstrated in Figure 1, it is apparent that the age distribution of SWSAHS is shifting over time with a growing proportion of the total SWSAHS population aged 45 years and over. Rates of change for people 65 years and older are higher with growth in younger groups being relatively static over the same period.

Demographic And Socio Economic Indicators

The demographic characteristics of SWS indicate the residents have more social disadvantage than other areas in NSW.

- Young population (24.5% aged less than 15 years compared with 21.4% for NSW);
- Aboriginal or Torres Strait Islander descent (1.2% compared with 0.57% for the rest of Sydney). SWSAHS also has 25% of Sydney's Aboriginal population;
- 34.4% of the SWS population was overseas-born compared to 23% for the rest of NSW, with even higher rates in Fairfield (53.5%), Liverpool (35.1%) and Bankstown (33.2%) LGAs;
- 28.5% of the SWSAHS population is from a non English speaking background compared to 15.7% for NSW. 36.5% of the population speak a language other than English at home compared to 18.1% for the rest of NSW);
- Unemployment (10.8% for SWSAHS compared with 8.8% for NSW);
- In relation to levels of education attained only 0.7% of the SWSAHS population had higher degree qualifications compared to 1.6% for NSW. 5.4% had post graduate diploma or bachelor degree qualifications compared to 9.3% in NSW;
- The SWSAHS population has a higher proportion of persons with incomes less than $31,200 (18.4% for SWSAHS compared to 16.9%for NSW) and a lower proportion of persons with incomes above $52,000 (2.6% for SWSAHS compared to 3.9% for NSW);

- Large population living in public housing with 10.1% for the SWSAHS population compared with 5.7% for NSW);
- 3.1% of the population received a disability support pension, 1.0% receive a carer's pension and 5.1% of the population are considered the Home and Community Care (HACC) target population;
- 17.3% of the Wingecarribee LGA's population over 65 years hold a Health Care Card, Pensioner Concession Card or a Commonwealth Seniors Health Card, compared to 9% of the NSW population over 65 years.

Source: Health in South Western Sydney Epidemiological Profile 2000

Utilisation Of Palliative Care Services

The NSW Health inpatient statistical collection system (ISCOS) does not adequately reflect palliative care utilisation across the full range of services, and provides information about inpatient care only. Whilst good palliative care baseline activity data is not available across all SWS Sectors there is some data that has been consistently collected in some Sectors.

Introducing the centralised registration system of palliative care patients, as proposed in the PCHP submission, will form a part of the Area's patient administration system and will provide good activity data for the Service in future ***(2.6)***.

Table 2 shows the demand for inpatient palliative care for SWS residents over the past 3 years.

Table 2 – SWS Resident Demand for Inpatient Palliative Care

	1997/98	1998/99	1999/00
Demand (episodes of care)	912	1373	1439
Demand (bed days)	10324	13000	12702
Average length of stay - days	11.3	9.4	8.8

Source: NSW Health FlowInfo v4.2Q3
**Includes day only patients*

Table 3 shows the inpatient activity in SWSAHS hospitals for palliative care.

Table 3 – SWS Resident Inpatient Palliative Care in SWSAHS Hospitals

Facility	Activity	1997/98	1998/99	1999/00
Braeside	EOC*	411	825	918
	Beddays	5170	6259	6628
	ALOS (days)	12.6	7.6	7.2
Camden	EOC	149	148	163
	Beddays	1104	1350	1879
	ALOS (days)	7.4	9.1	11.5
Other SWS Hospitals	EOC	107	167	159
	Beddays	681	1289	1262
	ALOS (days)	6.4	7.7	7.9
Resident Self sufficiency		73%	83%	86%

**Episodes of Care*
+Self sufficiency is the percentage of demand for episodes of care of SWS residents that is provided in SWSAHS facilities

The majority of the above admissions were for neoplasms. People with malignant diseases are the major users of palliative care services, with about 80% of activity for people with a cancer diagnosis. There is also involvement with people with other terminal diseases such as Motor Neurone disease, end stage liver and renal diseases, HIV/AIDS and multiple sclerosis.

In the period 1993-1997 cancer was the third most common cause of death in SWS. The majority of cancer related deaths occur in older people and are reflected in the service utilisation figures.

As can be seen from the above table self sufficiency has improved to 86%, while length of stay has reduced over the 3 years. The average length of stay in SWSAHS hospitals is low when compared to other units (Table 4). This reflects the high demand in SWS for palliative care beds, and is also a reflection of the model of care to provide symptom relief, stabilisation and maintenance care and then to discharge the patient back to the community.

SWS Residents in Other Palliative Care Units

The only indicator of flows of SWS residents for palliative care to other Area Health Services is to compare similar hospitals to Braeside Hospital.

Table 4 – SWS Residents in Other Area Health Services (Inpatient Units)

Facility	Activity	1997/98	1998/99	1999/00
St Josephs	EOC	155	138	129
	Bed days	2285	2641	1883
	ALOS	14.7	19.8	14.6
Calvary	EOC	22	25	16
	Bed days	321	357	289
	ALOS	14.6	14.2	18
Sacred Heart	EOC	24	12	5
	Bed days	384	193	177
	ALOS	16	16	35.4

Source: NSW Health FlowInfo v4.2Q3

Services in the community are provided by dedicated palliative care staff and these are measured by occasions of service (OOS) to give activity data. The following table gives an indication of the level of activity for some Sectors for the Palliative Care Service over the last 3 years.

Table 5 – Palliative Care Service Activity

Activity	Bankstown	Fair-field	Liver-pool (Hosp)*	Liver-pool (Comm)	Macarthur	Winge-carribee	Total
Referrals							
97/98	382	263	N/a	N/a	N/a	136	642
98/99	382	311	855	N/a	N/a	78	692
99/00	406	288	941	240	354	108	1290
Home Deaths							
97/98							
98/99	59	36		N/a	N/a	51	59
99/00	64	41		N/a	N/a	30	64
	60	24		23	65	48	60
Home Visits							
97/98	2042	1845		N/a	N/a	N/a	2042
98/99	2970	3336		N/a	N/a	N/a	2970
99/00	3733	3302		2046	656	N/a	3733
Tel Consults							
97/98							
98/99		1027					
99/00		892					
		944					
Total OOS*							
97/98	5414	2872	N/a	N/a	N/a	N/a	8314
98/99	6562	4228	2958	N/a	N/a	N/a	10762
99/00	7943	4246	3735	N/a	2316	277	14559

- *Occasions of Service*
- *Liverpool Hospital statistics include medical and nursing activity*

The differences in the above table reflect the lack of uniformity in data collection. This lack of uniformity will need to be addressed and appropriate strategies have been developed in this plan ***(2.6)***.

Projected Need for Palliative Care Beds

As demonstrated in the population projections and the socio-economic composition of SWS the number of elderly people is expected to rise steadily. While the number of new cancer cases is also projected to increase demand from non-cancer patients with respiratory disease, end stage renal disease etc will increase.

In 1998/99 there were 10,359 bed days utilised in designated palliative care facilities in NSW for SWS residents. At 90% occupancy this equates to 32 beds. With the increase in the number of palliative care beds at Camden associated with the Macarthur strategy, SWSAHS will have 30 designated palliative care beds open by the end of 2001. Bed planning for acute facilities will include a component for palliative care patients with acute care needs.

The Australian *National Strategy for Planning Palliative Care Services 1998-2003* has accepted a United Kingdom standard of 40-60 beds/million residents. This standard includes long term palliative care beds, that is care for up to 3 months. This equates to a need for between 31-46 beds in 1999, increasing to 34-50 beds in 2006, and 35-52 beds in 2001 for SWS.

Braeside Hospital experiences a very high occupancy rate that may change with the opening of the beds at Camden Hospital. It is considered there is an adequate supply of short-term palliative care beds in SWSAHS, although the availability of beds for long term palliative care patients remains an issue ***(3.9)***. Strategies to provide care for long term palliative care patients will need to be proposed that will not have a detrimental impact on the patient.

Access to Services

The findings of a Palliative Care Australia's census, conducted in 1998 on access to senior clinical expertise suggested poorer service availability in rural and regional areas. The census found that 60% of metropolitan services reported access to palliative medical specialist support and 80% reported access to clinical nurse consultant (CNC) level specialist nursing support. In regional areas, these proportions dropped to 36% and 61% respectively. Further, the census identified population based rates of admission to palliative care services as 30-35% lower in regional areas.

> *"Today, palliative medicine is the care given to patients at the end of life when much else has been tried, often over many years, and now their need is for comfort, dignity and a sense of usefulness, a respect for their personhood, and a reaffirmation of life, rather than a preparation for dying"*
> Oxford Textbook of Palliative Medicine, p8

In the Gleeson review activity at Braeside was considered as a proxy for access, but the review did not consider the beds available at Camden Hospital (7 beds up to September 2001). There are now 10 beds open at Camden Hospital. This will provide access to inpatient beds closer to home for residents in the southern parts of the Area, eg Wollondilly and Wingecarribee LGAs ***(2.3)***.

For some people it is more culturally appropriate to be cared for at home. Inpatient activity will not reflect choices actively made about place of care. In the Macarthur Sector the palliative care team has a close working relationship with Tharawal, and whilst care may be delivered in their own community there is opportunity for consultation by the palliative care team when required.

Considering the diversity of the SWS population strategies to address access levels in the more marginal population groups are required. Potential areas of focus are NESB, ATSI and paediatric palliative care populations, as well as younger adults with high levels of nursing dependency, long term care needs, HIV and non-cancer patients ***(2.4)***.

"Palliative care: … affirms life and regards dying as a normal process, … neither hastens nor postpones death, … provides relief from pain and other distressing symptoms, … integrates the psychological and the spiritual aspects of care, … offers a support system to help patient live as actively as possible until death, … offers a support system to help the family copy during the patient's illness and in their own bereavement."[ii]

When resources are limited it is imperative that relevant and appropriate priorities are agreed and strategies developed and implemented.[iii] It is important that from the outset palliative care is seen as integral to the care of those with cancer.

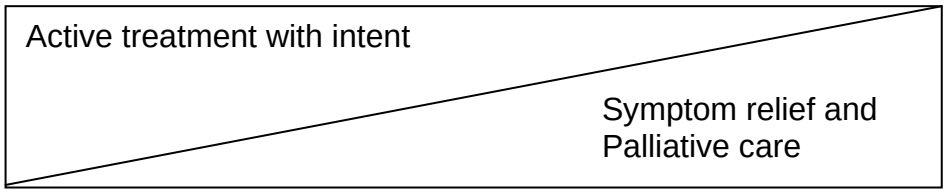
The relief of pain and other symptoms and the appropriate provision of psychological, social, emotional and spiritual support to the person and their families and carers is of paramount importance ***(1.3)***. To achieve this seamless continuum of care requires the participation and coordination of a range of services and providers.

Symptom burden reduction allows the person to live as normal a life as possible, reduces inappropriate hospitalisation and improves quality of life.

In order to facilitate better management of the dying phase we need to ensure timely identification of those who are actually dying, treat distressing symptoms and syndromes in the 'actually dying' phase, and allow people to die in the place of their choice.

The following diagram illustrates the proposed allocation of cancer resources in developed countries.[iv]

Figure 2 – Proposed allocation of cancer resources in developed countries



This model would be applicable to most non-cancer patients whose disease is incurable and prognosis is poor.

Model of Care in SWSAHS *(1.1, 4.4)*
The following diagram illustrates the model of care SWSAHS Palliative Care Services have adopted which the places the patient at the centre of the care continuum.

A strategy in Appendix I for the Area Palliative Care Service is to develop a mission statement that reflects the adopted model of care.

Figure 3 – SWSAHS Model of Care

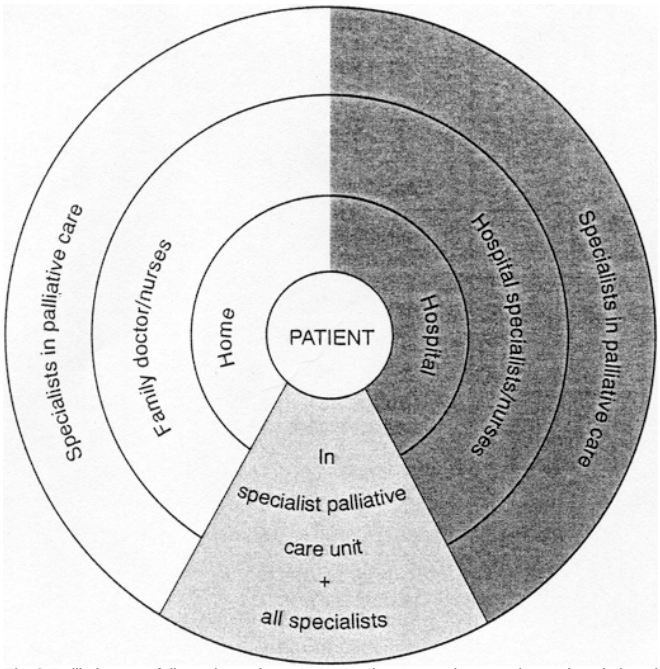


Fig. 2 'Palliative care follows the patient'. As any patient moves between home, hospital, and specialist palliative care unit he or she always has access to specialist palliative care. All that is needed is for the general practitioner or hospital physician/surgeon to call in the specialist in palliative care, whether that be a nurse or a doctor.

Organisation of Services

The Area is divided into 5 sectors with inpatient facilities in each Sector, and a teaching hospital at Liverpool. The designated palliative care inpatient units are Braeside Hospital (20 inpatient beds 7 days a week, and 2 days a week there is a day hospital with 10 places) and Camden Hospital (10 inpatient beds). There are outpatient clinics operating at Braeside, Bankstown and Liverpool Hospitals. There are also outpatient clinics planned for Camden and Wingecarribee. ***(1.4)***

The SWSAHS Palliative Care Service provide consultative and specialist inpatient services to the Area together with General Practitioners (GPs), public hospitals, community, nursing homes and private hospital services.

In addition to the hospital units there are community palliative care services located in every Sector, Palliative Care volunteer services, a therapy equipment loan pool, and a 24 hour call centre service to specialist palliative care advice will be in operation by the end of 2001.

Figure 4 – The Provision of Palliative Care

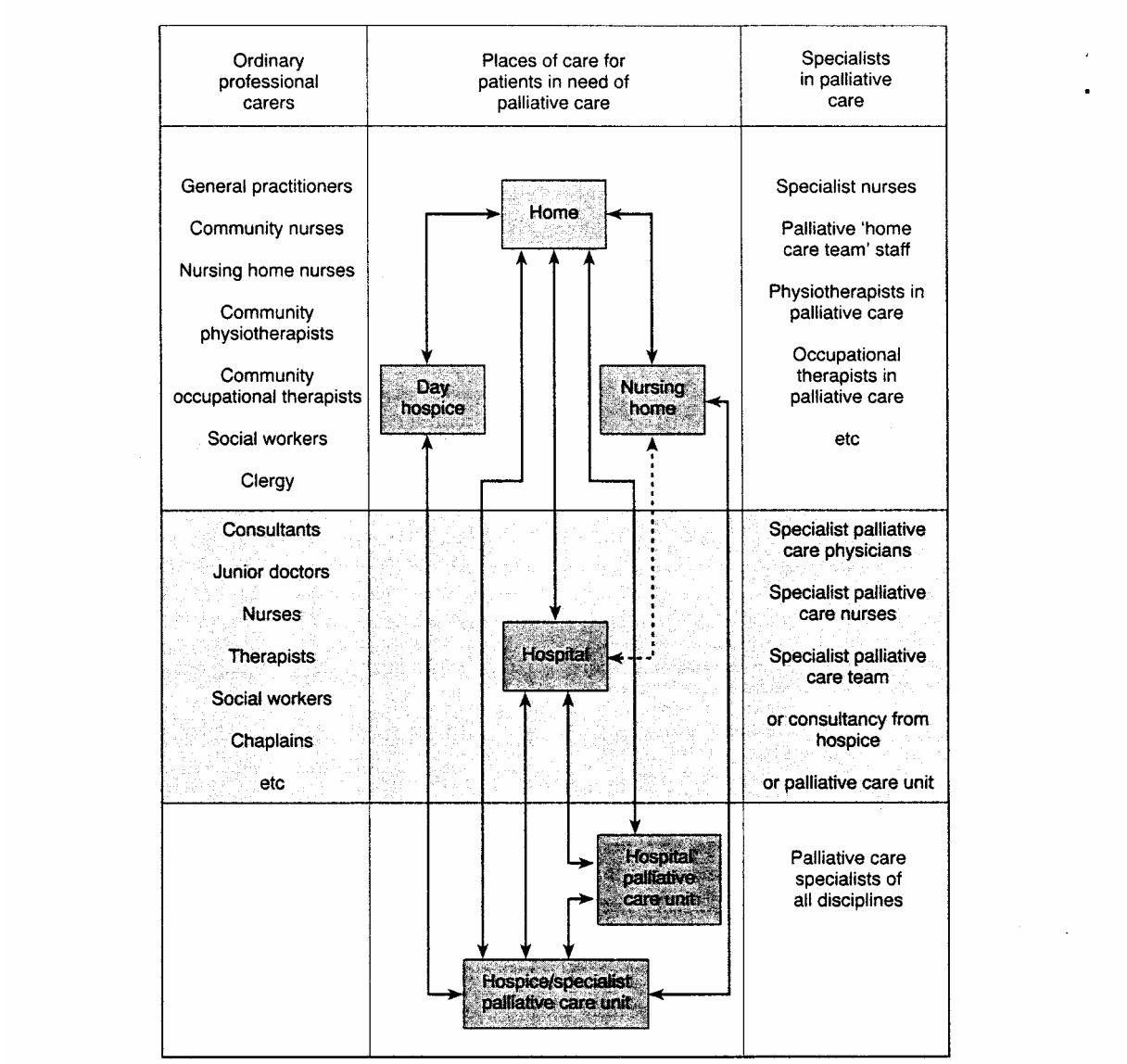


Fig. 1 'Palliative care follows the patient'. When the patient is at home the ordinary day-to-day professional carers are the general practitioner (family physician), community nurses, and therapists. The patient may move between his home, a nursing home, and a Day Centre, but always these are his carers, assisted if needs be by the specialists in the right column. If the patient goes to hospital the ordinary staff there also have palliative care specialists to help and advise them, in touch with those who assisted in the community. If admission to a specialist palliative care unit is needed, even if the patient leaves there to return to hospital, home, or nursing home, still there are palliative care specialists on hand.

The Gleeson Review made note that "the current organisation of services includes a different model of service provision in each Sector, different reporting structures, different levels of after hours support and different levels of access to social work, allied health and bereavement services. It was also noted there are no consistent area-wide policy and procedure documents, data collection is not consistent and the constitution of palliative care teams differed across Sectors. Strategies have been developed in the plan to address these issues through Service Level Agreements (SLA) with Sectors. A Service Level Agreement is already in place in the Liverpool and Macarthur Sectors ***(3.12)***.

Workforce *(4.1)*

The Area Director of Palliative Care Services, reporting to the SWSAHS Area Executive Team (AET) through the Director of Medical and Clinical Services is responsible for the planning and development of services. The Area Director also undertakes a significant clinical load.

There is a palliative care community nursing team in each Sector with line management through individual Sector structures.

The Gleeson Review highlighted the very large increase in new medical referrals over the last 3 years. The review concluded that "in addition to two palliative care medicine positions to be recruited in Macarthur, there is a need for an additional 1.5 FTE Staff Specialist positions across the Area to meet any unmet need and future demands."

An additional staff specialist will be appointed to Liverpool Hospital in the first quarter of 2002 and an additional .5 FTE staff specialist will be recruited to Bankstown Hospital in the last quarter of 2002. There has been one appointment of a medical staff specialist, based in Macarthur/Wingecarribee, and the second position will be recruited to coincide with the opening of the 4th Linear Accelerator at Campbelltown Hospital and the Macarthur Cancer Therapy Unit in 2003.

Braeside Hospital is a part of the Sydney Institute of Palliative Medicine training rotation, recommended by the College of Physicians, and ideally Macarthur and Wingecarribee will be included in this rotation. This would enable a sharing arrangement with Community Health for the development of outpatient clinics in these Sectors ***(3.4)***.

> *"Patients should end their lives in the place most appropriate to them and their families, and where possible have choices in the matter … continuity of care can be maintained in the midst of change if there is effective communication and easy movement between different settings"*
> Cicely Saunders: Oxford Textbook Foreword pviii

Appendix II details the proposed governance structure and Appendix III gives the current and proposed staffing levels as endorsed in the budget enhancement process and the PHCP submissions. The proposed staffing enhancements will bring SWSAHS closer to staffing levels of the other metropolitan areas with similarly sized populations ***(2.2)***.

Consumer Consultation & Participation

Braeside Hospital has a consumer Participation Committee for which consumers were recruited through advertisements in the print media. The committee has developed terms of reference and it meets every 3 months where projects and issues are discussed and actions recommended.

There are three Sectors (Camden, Wingecarribee and Bankstown) where there is a greater level of community participation in palliative care services due to the existence of local groups, who have a particular focus on cancer.

In Wingecarribee the Cancer Patients Assistance Society provides assistance to cancer patients by organising transport, respite care and financial assistance when required. There has also been a recent approach to the Palliative Care Service from a community

member wanting to establish a foundation in the local area to provide residents with access to respite care, education and transport etc.

In the Camden LGA there is the Jennifer Eggins Cancer Support Fund for local residents that provides equipment for loan, financial assistance, after school care for children, child school uniforms etc.

Palliative Care Sector Services

The following is a summary of discussions held with Sector Palliative Care staff. This information is a summary demonstrating individual service delivery at Sector level. The information also includes expressed or felt need at the Sector level and has been the basis for identifying key issues and gaps. The reader is referred to The Gleeson Review for more detailed Palliative Care Sector service information.

Fairfield Sector

1. The equipment pool at Fairfield is run by the Occupational Therapy department at Fairfield Hospital. Fairfield palliative care patients have very good access to a range of equipment. There are no large items available, such as hospital beds.
2. Only Braeside and Fairfield community services are collecting SNAP data.
3. Client referral in Fairfield are taken directly by palliative care services and not through the general community health intake system. Waiting times have reduced from an average 11 days to 1.6 days. The performance indicator being used is the percentage of new clients contacted within 48 hours of referral
4. FRF Division of General Practice ran a series of 4 GP education workshops together with the Area Palliative Care Service. Feedback was a request that this be repeated in 12 months.
5. Palliative Care Mutual Support Group (PCMSG) has been formed from interested GPs. This core group will do home visits and support other GPs in the Division at times of leave etc when requested. The core group is culturally and ethnically diverse. A sub committee of the Division of General Practice has been formed from the PCMSG members that will be chaired by the divisional chair with representatives from palliative care. Their terms of reference include education for GPs and a 2-monthly workshop for case discussion and presentations will take place.
6. The Department of General Practice at Fairfield Hospital is undertaking research to evaluate the Enhanced Primary Care items as to whether the process of care planning has improved. The Department of General Practice at Fairfield Hospital and Fairfield Community Palliative Care services is providing assistance for the project.
7. There is an established relationship with nursing homes in the LGA to provide nursing consultancy and education to staff.
8. The ACAT respite care system is used where patients fit the relevant criteria
9. The Carer Respite Centre can provide short term (in terms of hours not overnight) respite in the home.
10. There is some access to mental health services but it is not optimal. There is more access for the older age group (>65) as there is an aged care psychiatrist at Braeside and an Aged Care mental health nurse.
11. Paediatric referrals are usually made to the Paediatric Outreach Service, run through the Fairfield Community Health Service who then consult with the palliative care service. There is one paediatric trained PC staff member on the team.

Identified Issues and Gaps

1. SNAP data collection has no local support
2. Special needs population groups
3. There should be a single point for information and coordination of care
4. Respite in nursing homes is not suitable for younger people
5. A review to identify any under-represented populations groups in the Fairfield Sector for palliative care referrals needs to be undertaken
6. Access to mental health services needs to be improved

Liverpool (community palliative care services at Hoxton Park)

1. Anyone with a diagnosis of cancer are referred and then assessed by the team as to whether referral to another service is required eg to PHNs for wound dressing.
2. First home visit to referred client is always done in conjunction with a Primary Health Nurse
3. Referrals go through the general intake system and this happens every day. Contact with the person referred is always made within 48 hours. There are some direct referrals made but mostly referrals go through the general intake system
4. Information for clients is not targeted to specific language groups
5. Chronic & complex funding has funded an additional RN position for Liverpool community which has been recruited
6. Equipment pool is located at Hoxton Park and it is only used by the palliative care service. There are items such as commode chars, wheelchairs, and walking sticks. There is a hospital bed available for loan but no transport available to get it to clients – this has to be arranged with a private company and carries a cost. PADP are not funded to provide equipment to palliative care clients
7. The CNC has met with the Director of the Liverpool Division of GPs with a view to undertaking some education sessions for GPs on palliative care
8. The respite care service at Liverpool run by ACAT is accessed. There is also access to respite care provided by Hammondville Nursing Home. Occasionally referrals are made to Calvary for long term respite care
9. There is an Aboriginal Day Centre at Hoxton Park and the palliative care team work closely with the Aboriginal Health Workers
10. There is a community based paediatric outreach service that refers to the Palliative Care service. Joint visits to clients occur and there is good liaison between the Palliative Care service and the paediatric case managers
11. SNAP is not used. There is a palliative care database used

Issues and Gaps

1. Systems need to be put in place to improve GP coverage for palliative care patients in this Sector
2. Access to drugs after hours
3. Education sessions for local GPs on palliative care
4. Access to carer respite needs to be improved

Wingecarribee

1. The CNC provides services to the hospital and in the community with backup from the Primary Health Nurse team, as well as a consultancy service to nursing homes, retirement villages and private facilities in the Sector
2. Physiotherapy is provided by the hospital physiotherapists after referral from a relevant medical officer as a part of the Sector's Transitional Care Program (TCP). The aim is to avoid unnecessary acute hospital admission

3. Occupational Therapy services are available in the community
4. The generalist Social Worker in the community also takes palliative care referrals
5. Bereavement Counseling is provided by an NGO
6. Intake is through the general intake system and direct referrals are also taken. This will change when a full time intake officer is employed in the near future
7. Malignant and non-malignant illness are seen where the goal of care is quality of life
8. Home visits are provided from 8.30 am to 10 pm M-F, and for planned visits between 8.30 am and 10.00 pm on weekends and public holidays. The Wingecarribee TCP covers after 5pm to 8.30 am next morning. TCP also cover on-call requirements
9. Interpreters are rarely required in Wingecarribee. Area Interpreter Services are used
10. Cancer Patients Assistance Society has an equipment pool solely for the use of palliative care patients. If a bed is required these can be obtained from the hospital. A special mobile chair that patients can stay in for long periods is also available for loan. There are mobile oxygen concentrators available and a supply of mattresses. Equipment is maintained by the Loans Officer at Bowral Hospital
11. There are local fund raising activities undertaken mostly though by the Cancer Patients Assistance Society (CPAS)
12. The CPAS runs the Jean Colvin Hospital in Darling Point to where patients have the option to stay if undergoing treatment in the inner metro hospitals
13. The CPAS will also provide financial assistance for residents when required
14. Keeping the profile raised of the CPAS and recruiting further volunteers is important for service provision in this Sector
15. The rural assistance scheme for residents further than 200 km from treatment services does not operate in Wingecarribee even though the most southern border of the shire is approximately 50 km from Bowral
16. The CNC manages an on-call service and the 1300 service (to be funded through the Priority Health Care Program) is being implemented
17. The GPs in the Sector with palliative care clients do home visits
18. Access to after hours drugs is available through a network of local pharmacies and if needed the GP who is on-call for the Sector writes a script for the required drugs
19. Data collection - a hard copy of patient admissions, deaths and demographics is kept
20. The Palliative Care Volunteer Service has 2 volunteers in this area, but only 1 is currently active
21. The Red Cross Volunteer service is also available. These volunteers are not palliative care trained but training would be supplied where interest is shown
22. There is a hospital-based Pastoral Care Committee with a volunteer Pastoral Care worker available for Wingecarribee residents
23. The Pastoral Care Committee representatives have different backgrounds, not necessarily health workers
24. Medical support for palliative care patients in the Sector is obtained either from Braeside or Camden when specialist medical advice is required. The GP is contacted in the first instance
25. A paediatric outreach program has been commenced in the Sector and it is expected that links with this service for paediatric cancer patients will develop over time

<u>Issues and Gaps</u>

1. There is a lack of guidelines or help for carers available in terms of what might be expected of them in their role
2. There is a need for long term care and long term respite care in the Sector
3. There are not formalised links with the private hospital for palliative care medical consultancies

LIVERPOOL (Hospital based services)

1. Provide services to palliative care patients in hospital or patients attending outpatient clinics at Liverpool Health Service
2. The service identifies patients where familial risk factors are important and approaches family members eg at diagnosis or as early as possible
3. Hospital has an equipment loan pool and there is no problem with equipment. Most equipment loans are organised through the Occupational Therapists
4. After hours drugs in the hospital are available and the patient is only supplied with enough to go home with
5. There will e a Staff Specialist in Palliative Medicine recruited for the Liverpool Health Sector
6. Good relationship with the Emergency Department to help avoid a patient being admitted
7. Respite to a nursing home is not often appropriate because the patient need expert palliative care and therefore there is a longer inpatient stay
8. Emergency Carer Respite for is available. No planned short term care can be offered unless a volunteer is available
9. If there is a 'package' of care, for example some aged care packages will sometimes include short term respite care
10. Research interest in how close to death the patient's last treatment was and the place of death. This is currently in the discussion stage.

<u>Issues and Gaps</u>

1. There is no long term care for palliative care patients
2. The services for younger patients, especially those with GBM need to be addressed
3. There is a time lag between notification of the need of a patient going home who requires S8 drugs and the drug being available from the pharmacy
4. Patient information needs to be made available to other service providers particularly PHNs
5. Access to drugs is particularly important for patients discharged from hospital, especially at weekends and there is not a consistent practice in acute hospitals for the supply of medication

Bankstown

1. Consultancy services are provided to Bankstown Hospital
2. There is a new part time palliative care medical position being appointed in September 2002
3. Bankstown is on the border of 3 AHS' – Western, Central and South Eastern Sydney Area Health Services. There is a lot of liaison work with each AHS so that all the information on a patient is available. There is an amount of non-standard protocols and procedures across each Area. Communication mechanisms are not good
4. Currently 3 positions down and there are problems with recruitment
5. Referrals are direct for out-of-Area and in-Area is through the general intake system, as well as direct referrals
6. Arabic, Vietnamese and Italian are highest NESB groups seen and information on the palliative care service in Bankstown are being developed in these languages
7. More promotion of available services would have to be coincided with more staff
8. Use of the interpreter service is sometimes difficult as you need to book an interpreter up to 5 working days in advance for the main 3 languages when you need to be able to have an interpreter available within 24-48 hours of a new referral.

Protocol is not to see patients without an interpreter but this cannot always be accommodated
9. Some local GPs will do home visits but they are getting overloaded
10. St Joseph's Hospital take patients for respite care for up to 1 week to 10 days
11. Loan equipment pool is based at the hospital, there is no charge, but there are not enough hospital beds available for loan
12. Use the Area volunteer service and a recent inservice has raised the profile with the community teams
13. UWS at Milperra has a Bereavement Counselor who will see people with complicated grief

Issues and Gaps

1. Access to interpreters within an appropriate timeframe needs to be addressed
2. A program with the Bankstown Division of General Practice is needed to increase the partnership with GPs
3. An increased number of volunteers available
4. Need access to more loan hospital beds for patients

Macarthur

1. Client referrals to community Palliative Care team is either through PHN Intake Coordinator or direct to the Palliative Care team. Patients are then registered for after hours palliative care service and inpatient unit admission
2. Time to first contact for all new referrals is now within 48 hours which meets PCA standards
3. Camden Palliative Care Unit is collecting SNAP data
4. Jennifer Eggins Cancer Support Fund for residents of Camden provides equipment for loan, financial assistance, after school care for children, child school uniforms etc
5. Macarthur has an equipment loan pool based at Campbelltown Hospital that is reasonably well stocked
6. The community team incorporates a full-time Social Worker, and the allied health team members based in the inpatient unit also have community links
7. Macarthur HS has a service level agreement with the Migrant Resource Centre for all services delivery
8. The SWSAHS Interpreter service is well utilised
9. There is a good working relationship with Tharawal ATSI Health centre
10. The community Palliative Care team provide a consultative nursing service 8.30 am to 5.00pm M-F
11. Macarthur Professional Nursing Agency provide on-call after hours palliative care nursing service from 5pm to 8.30 am and 24 hours on weekends. Call to the after hours service are triaged by the Palliative Care Inpatient Unit staff, and if required an after hours nurse is called out
12. Local clergy provide visiting services to the Camden Hospital Palliative Care Inpatient Unit
13. There are good links with palliative care volunteers who come to the ward as well as to the patient's home
14. Community Options provide financial assistance and nursing home respite care if funds are available
15. There is an established relationship with nursing homes in the LGA to provide nursing consultancy and education to staff
16. The ACAT respite care system is used for access to in-hour day and overnight respite care for palliative care patients (Reslink)

17. GP education workshop have occurred in conjunction with the Macarthur Division of General Practice
18. Access to the Liverpool Cancer Therapy Centre patient records is now available on a read only basis to Braeside and will be extended to Camden in the near future.
19. A Medication Access Working Party has investigated difficulties in access to palliative care medications, particularly after hours access. Strong links have been developed with local pharmacies to improve access to after-hours / crisis medications
20. There are no designated bereavement staff in Macarthur

Issues and Gaps

1. PCA standards for bereavement care cannot currently be met in Macarthur
2. Admitting rights for Palliative Care physicians and access to beds other than at Camden and Braeside – ideally there would be beds in Liverpool and Bowral
3. There is inadequate Junior Medical Officer cover on the ward
4. Placement for younger patients in long term beds is a problem
5. There is a shortage of hospital beds for loan
6. Lack of transport is an issue in Macarthur
7. Access to appropriate mental health services and paediatric palliative care services
8. Money from Cremation certificates is not directed back into the service
9. GPs access to their registered palliative care patients' records held at the CTC is needed
10. A dedicated bereavement care worker would promote consistency and a uniform approach to care of the bereaved in Macarthur
11. The Camden inpatient unit serves three large rural areas - A community / hospital outreach service could improve access. The service would need MD, nurse, blood collector, mobile x-ray equipment. Possible use of mobile vans located in the Macarthur Sector

There are a number of key issues that need to be addressed that will improve the provision of palliative care services in SWS. The recent budget enhancements to the service from growth funds and the Priority Health Care Program funding will assist in delivering more effective services across the Area, and increase access to those SWS residents where access is an issue.

Workforce
There were four significant issues highlighted in the Gleeson review regarding workforce. These included a lack of palliative care medical staff and allied health staff to service the Camden unit; a mal-distribution and under-resourcing of nursing services within the community sectors and an overall lack of allied health staff.

The budget enhancements to palliative care services, as well as the additional nursing staff associated with the PHCP will significantly boost the palliative care staff within the Area.

Partnerships
Partnerships need to operate at a number of levels including with the individual and their carers, specific population groups and with those providing primary and specialist health care.

The Palliative Care Service provides a consultancy service to General Practitioners working in SWS and the introduction of the Enhanced Primary Care items offers an opportunity to support the local Divisions of General Practice to develop protocols for family visiting and case conferencing ***(1.7)***. This will also assist in introducing Area standards of assessment and care planning ***(1.8, 3.6)***. It is important to have strong communication links with GPs in SWS ***(1.6)***.

Timely access to the appropriate medications for palliative care patients is important, particularly when a patient is discharged back to the community. Strong links with hospital and community pharmacies and GPs for the provision of medications need to be strengthened to ensure a patient has access to required medications ***(1.9)***.

Partnerships with other Area Health Services providing inpatient care for SWS residents also need to be developed and strengthened ***(3.10)***.

A number of specific population and disease groups would benefit from the development of strategies targeted to their particular needs. These groups include the younger adult age group, ATSI and NESB populations, paediatric and non-cancer patients, patients with disabilities and brain injury patients. Another group for which few services are available are long term patients living in the community, but not in their own homes eg hospitals and nursing homes.

There is a ‘priority’ system in place for using interpreter services for palliative care patients. Often it is not possible to secure interpreter services within the necessary timeframe, and there are an increasing number of languages to be covered ***(2.8)***.

Whilst there are particular target groups in the general population developing, and where they already exist, strengthening partnerships with other service providers working within and outside of the Area Health Service will also need to be addressed.

The Palliative Care Service provides consultancy services to nursing homes and hostels operating in SWS. The development of skills for staff working in these community settings is important, particularly as the numbers of palliative care patients will continue to reside, and often die, in these residential settings.

The NSW Health Palliative Care Framework identified the need to promote networks between metropolitan and rural palliative care services. The Area Palliative Care Service could support the development of a network for palliative care support and consultancy to those rural Areas with traditional referral patterns to SWSAHS ***(1.14)***.

Equipment Loan Pool *(2.11)*

Access to a loan equipment pool varies in each Sector. Some loan equipment items are difficult to obtain, as there are only a few available, viz hospital beds for home use, oxygen concentrators and the long term supply of items such as incontinence pads etc. Strategies to address loan equipment access, particularly for high cost items will be developed.

Education and Research *(3.1, 3.2, 3.3, 3.4, 3.5)*

Education

The SWSAHS Palliative Care Service will need to comply with the Standards for Palliative Care Provisions from Palliative Care Australia, Standard 5 *"the service is committed to education for its team and the wider professional and local community".* This standard has 4 criteria associated with it that are access to resource materials, leadership provided by staff within the serve, continuing education for staff and volunteers and outreach education for professionals and the community where appropriate.

SWSAHS has developed a learning program for Junior Medical Officers and there are formal educational sessions from the Clinical Fellow provided to new Registrars. These educational programs aim to maintain intellectual stimulation and alleviate any sense of isolation that clinicians may experience.

An educational program has also been developed for palliative care nursing staff that is held bi-monthly with presentations from a local and a visiting speaker. These sessions cover a variety of topics including new medications available and their use, new modes of delivery of medications, and there is also a 5-part series on blood tests.

A clinical meeting is also held every week followed by a journal club, and one day a month is devoted to staff support in terms of clinical supervision.

Educational sessions are also provided to staff of nursing homes and an assessment as to the most effective program will commence shortly.

Identified gaps in terms of education to key stakeholders are the patients, their carers, General Practitioners, the general community and specific community groups. The focus of this education would include information about death and dying, services

available locally and services elsewhere in the state that can be accessed by residents eg Camp Quality for children. ***(1.5, 1.6)***

Where there are gaps in services for specific population groups such as the younger adult population, particularly those with young families, education programs that raise the general community awareness of the need for palliative care for this population could be used to engage community assistance. Rural communities such as those in SWS often have a network of organisations engaged in assisting their residents.

This type of educational program will need to coincide with a raised awareness of palliative care services. Targeted media releases can help achieve this.

Research (3.8)

The Area Palliative Care Service is actively involved in undertaking research projects that have the objective of improving practice and service delivery. These projects also include ones for audit and quality improvement. The Clinical Fellow in Palliative Care is an Area-wide appointment and has dedicated time allocated for research.

A number of projects due for completion will be submitted for publication in recognised journals over the next 1-2 years. The development of new projects within the Palliative Care Service has been fostered, as well as collaborative projects with other SWSAHS services.

The SWSAHS Palliative Care Conference has been a platform for presentation of current projects and further presentation at international conferences is also anticipated on completion of the study.

The following table provides a list of Palliative Care Service research projects

Table 6 – Palliative Care Research / Audit / Quality Improvement Projects

Project Description	Project Progress
1. Double Blind Randomised control trial of topical morphine for painful ulcers	Patient recruitment commenced
2. Audit – accuracy of PR examination versus abdominal x-ray to assess faecal loading	Data collection 80% complete
3. Nocturnal Hypoxiz pilot study	Awaiting patient recruitment to recommence in 2002
4. Review of Anaesthetic intervention in palliative care patients	Report due for completion December 2001
5. 1300 number improving access for palliative care clients	• initial pre 1300 data collected and analysis in process • post 1300 data for first 3 months due for completion January 2002 • patient satisfaction survey to be conducted January 2002
6. RMO orientation package	Information package developed – for ongoing feedback
7. Survey of palliative care practitioners regarding prescribing practice	Complete
8. Audit on management of constipation in inpatient units	Complete
9. Bowel chart audit	Abandoned due to database problems
10. Comparison of glycophrrolate vs hyoscine for rattly breathing	Study abandoned due to issues obtaining consent
11. Needs analysis regarding palliative care in SWS nursing homes	Literature search

Fund Raising
Apart from funds received through bequests and donations there has been no fund raising activities taken up on a formal basis. Opportunities to raise additional funds for palliative care services need to be identified and appropriate strategies developed.

Information Management Technology & Telecommunications (ITT&T) ***(4.2)***
A Palliative Care area-wide, networked database is being developed in conjunction with the Area Information Services Department. This database will be compatible with other Area databases and will include an interface with the proposed Area Clinical Cancer Registry.

It is also planned to implement a Resource Scheduling Module as a part of the SWSAHS's Cerner PASS implementation that will allow patient scheduling to a variety of clinics and treatment services.

The following areas have been identified as requiring development to provide the full range of palliative care services in SWSAHS. This is to ensure the needs of all patients requiring palliative care are being met, as well as meeting the imperative of compliance with the Palliative Care Australia Standards. It is anticipated that these areas will be developed over time and will be ongoing ie continuing beyond the timeframe of this strategic plan.

Volunteer Services *(2.9, 4.5)*

There is a part time SWSAHS Volunteer Coordinator who identifies, recruits and provides training for volunteers throughout the Area. There will be a need to increase this to a full time position over the next 2-3 years, with a possibility of further expansion in the future as the need arises. There is also a Volunteer Coordinator located at Braeside Hospital and the last training sessions for volunteers that was undertaken was carried out jointly.

Bereavement Care *(1.11)*

A project was undertaken during 2001 by the Bereavement Coordinator at Braeside Hospital Palliative Care to assess the needs for bereavement care in SWSAHS. The project report made recommendations in 5 key areas. These were

- the introduction of a bereavement care assessment tool within SWSAHS;
- the nomination of a key health care worker within each Sector to be responsible for bereavement issues;
- the opportunity for the multidisciplinary team in each Sector to discuss the deaths of patients;
- the formation of a bereavement committee; and
- the assessment of the needs of the NESB community.

Allied Health *(1.13, 4.3)*

There are a number of allied health staff working as a part of the multidisciplinary palliative care teams, both community and hospital based. An unknown factor in these settings is the service delivery to palliative care clients by the generalist allied health teams. The Gleeson review highlighted the need to increase the number of allied health professionals in the palliative care teams, particularly in bereavement care.

An analysis of the generalist allied health team involvement with palliative care clients and the current level of service delivery will need to be carried out prior to recommendations on the exact palliative health allied health workforce requirements.

Pastoral and Spiritual Care *(1.10)*

An area wide approach to the provision of pastoral and spiritual care needs to be developed to provide a total care package for clients, but also to comply with Palliative Care Australia standards, particularly the standard relating to the Spiritual Domain.

There is a Chaplain who works as a part of the Bereavement Service at Braeside Hospital and spends a majority of time on death, dying and bereavement care. There are memorial services held about 6 times a year with a focus on family and friends, particularly those who have been unable to attend the funeral. The Chaplain also undertakes a resource role for contact points to different religions.

The Chaplain provides in-service education to staff in the Area and has developed a number of resources. Staff have expressed a need to know how to assist people spiritually and so more resources will be developed.

Carers are also grappling with bereavement that has already started and there is little support in terms of spiritual or psychological care for them and for the patient facing their own death. More mental health and psycho-social services for all connected with palliative care is also required.

There is a need to provide spiritual development awareness programs to help staff increase in knowledge, skills and comfort with dealing with this area. This is seen as a high priority by staff.

In Bowral a member of the local Pastoral Care team (volunteer) provides a link with the various churches in the community and refers people on to denominational / other faith representatives as appropriate.

A uniform and structured process for accessing pastoral care in the Area is needed. A directory of pastoral care resources in each Sector, and a register of trained spiritual / religious support people (clergy or lay) in the community also needs to be developed.

Staff Support *(3.10)*

Palliative Care, by definition is concerned with whole person care, that is it addresses physical, emotional, intellectual and spiritual needs. It is thus critical that Palliative Care health care professionals have a good insight into their own emotional/psychological issues and the opportunity and resources available to enhance and develop their self knowledge and understanding. This is needed to minimise the dangers of psychological projection onto patients and their families, and to maintain staff health and minimise 'burnout'. The Palliative Care Australia's standards recognise this need under Human Resources Management.

Currently at Braeside there is a pilot nurses support group using 'story telling / story listening' facilitated by the Bereavement Coordinator; there is an Employees Assistance Phone Service available for staff to access at time of stress; and individual staff members organise and pay for their own individual clinical supervision.

Staff support and clinical supervision should be encouraged, available and resourced. This is consistent with international trends and has long been accepted as fundamental for professionals working with psychosocial issues. Also processes are required for support and 'debriefing' following specific stressful and/or crisis situations as they arise.

Creative Therapies

The use of creative therapies in health is not a new concept and often used in diversional therapy for programming leisure opportunities for people with specific needs.

As an example, in SWSAHS the *'Arpilleras Workshop'* used art to help break feelings of isolation among Latin American women. The *Arpilleras Art to Break Isolation* is now owned by Liverpool Hospital and forms a part of the decoration of the Caroline Chisholm Centre for Women and Babies. There are 9 works from this group included in the permanent exhibition.

Music therapy is also used in a number of settings to help participants express their feelings and shared experiences and to promote a sense of wellbeing. In Victoria there are a number of music therapists employed in palliative care services.

There is an opportunity to explore creative outlets for the psycho social needs of patients, carers, families and friends of those in need of palliative care.

Conclusion

There is a need for the Area Health Service and Area Palliative Care Services to develop a pro-active response to the forecast ongoing growth in demand for palliative care services in SWS. This issue is closely related to the projected growth in cancer incidence in SWS and the ageing of the population.

This Plan builds on and consolidates the recent expansion of services to be able to provide more than just a 'basic' palliative care service in SWS. A focus of the expansion has been in additional palliative medicine clinicians. Developing partnerships at a number of levels, including with the individual and their carers, specific population groups and with those providing primary and specialist health care are critical to providing a total care package.

A range of strategies has been developed in relation to the issues identified in this Plan and these are presented in the following section.

Appendix I – Detailed Strategies and 3-Year Implementation Plan

GOAL 1: HEALTHIER PEOPLE

SERVICE OBJECTIVE: To promote changes conducive to maximising wellbeing, symptom control and pain relief in the SWS community

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
1.1	Develop an Area Palliative Care mission statement	Mission statement developed	Area Palliative Care Service	June 2002	None		**KC5.4**
1.2	Implement Palliative Care Australia standards	PCA standards implemented	Area Palliative Care Service	Ongoing	Palliative Care Coordinator	Enhancement funding/ PHCP	KC2.1
1.3	Pain and symptom control are maximised for palliative care patients	Assessment tools incorporated into medical and nursing assessment	Area Palliative Care Service	Ongoing	Palliative Care Coordinator	Enhancement funding/ PCHP	KC5.3
1.4	Provide consultancy services and outpatient clinics to all SWSAHS Sectors	Successful recruitment of staff	Area Palliative Care Service	March 2003	Additional medical and nursing staff	Enhancement funding/ PCHP	KC3.4
1.5	Implement GP education program for all Divisions of General Practice in SWS	Number of GPs attending education sessions	Area Palliative Care Service / Division of General Practice	Ongoing			KC2.2
1.6	Improve and maintain communications with GPs and provide support	Improved communication links	Area Palliative Care Service	Ongoing			KC2.2
1.7	Support protocols for family visiting / case conferencing with GPs through the Divisions	GPs supported by palliative care teams	Area Palliative Care Service	Ongoing			KC2.2
1.8	Ensure an area-wide standard of assessment and care planning	Standardised assessment and care planning in place	Area Palliative Care Coord / CNCs	Ongoing			KC5.3
1.9	Undertake negotiations with hospital and community pharmacies and GPs to improve patients' access to medications including out of hours access	Improved patient access to medications	Area Director Palliative Care / GMs / Divisions of GPs	Dec 2002			KC2.2
1.10	Review spiritual care services and propose an Area model	• Review complete • Recs. implemented	Area Director Palliative Care / Chaplain	Feb 2002 & ongoing	Spiritual & Pastoral Care Committee		KC5.4
1.11	Review bereavement counselling services and propose an Area model	• Review complete • Recs. implemented	Area Director Palliative Care /	Feb 2002 & ongoing	Bereavement Care Committee		KC5.4

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
1.12	Develop links with international Palliative Care centres	• Links developed & reciprocal support, education and information exchange • Membership of international organisations	Palliative Care Service	Ongoing	None		KC2.1
1.13	Investigate allied health service delivery to palliative care patients	• Review complete • Recs. Implemented	Area Director Palliative Care / Area Allied Health Advisor	June 2003 June 2004	None		KC3.3
1.14	Develop links with appropriate rural areas to support their access to specialist services	Formal links developed	Area Director Palliative Care				KC2.1

GOAL 2: FAIRER ACCESS

SERVICE OBJECTIVE: To ensure that all patients requiring palliative care services who live in SWS have equitable access to care for their illness; and that care is provided in a manner which is appropriate to the needs of community groups and individuals within SWS

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
2.1	Annual review of growth in referrals to refine forecasts for the following year and identify impact on Area for delivery of palliative care services	Review performed annually	Area Palliative Care Service / Division of Planning	Annual			KC3.1
2.2	Refine and confirm workforce requirements for projected demand and facility driven enhancements	Training, recruitment and retention strategies developed	Area Palliative Care Service / Area Human Resources	2001/2002 and ongoing			KC6.1
2.3	Increase hospital and community capacity to meet demand	Expansion of medical and nursing services based in hospital and in the community; opening of Camden inpatient unit	Deputy CEO, GMs	2001/2002		Growth funding for 2001/02 and 2002/03 and PHCP funding	KC4.4 KC3.4

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
2.4	Undertake a needs assessment for specified population and disease groups as identified by each Sector	Needs assessments complete and strategies developed Liaison with relevant staff formalised	Area Director Palliative Care / Area Palliative Care Coordinator	2002/2003			KC3.3
2.5	Palliative care clinics are developed across the Area to meet local needs	Clinics in operation	Area Director Palliative Care / GMs	Dec 2002	Clinic space and administrative support	To be identified	KC3.1
2.6	Develop palliative care database	• Area PC database established and operating • Links established to the Area Clinical Cancer Registry	Director Information Services / Area Director Palliative Care	June 2002	Data Manager	To be identified	KC2.3
2.7	Implement 24 hour access to specialist palliative care advice	• 1300 telephone number in operation • Telephone advice service evaluated	Area Director Palliative Care / Clinical Fellow	January 2002		PHCP	KC2.3
2.8	Examine the use of interpreters and identified issues	• Issues identified • Recommendations made	Area Director Palliative Care / Area Director Interpreter Service	December 2002			KC3.3
2.9	Recruit additional NESB and ATSI volunteers	• Increase the Volunteer Coordinator position to full time • Increase the number of volunteers	Area Director Palliative Care / Volunteer Coordinator	Ongoing		Budget enhancement	KC3.3
2.10	A feasibility study is undertaken with Liverpool Health Service to establish the need for designated palliative care beds in Liverpool Hospital to support the consultative service	Feasibility study undertaken	Area Director Palliative Care / GM Liverpool Health Service	June 2003	Staff specialist in Palliative Medicine	Enhancement funding	KC5.4
2.11	Review access to loan equipment, particularly hospital beds and transportation to patients' homes	• Review complete • Issues identified • Recommendations made	Area Director Palliative Care / GMs / CNCs	June 2002			KC5.4
2.12	Implement and integrate the Chronic and Complex Care initiatives throughout SWSAHS	• Program initiatives implemented in Sectors • Program indicators met	Area Director Palliative Care / Area Palliative Care Coordinator	June 2002		PHCP	KC2.2

GOAL 3: QUALITY AND SAFE HEALTH CARE

SERVICE OBJECTIVES: To ensure that all residents using palliative care services have access to individualised palliative care on the basis of care needs and an individual's informed choice. To ensure all residents have access to optimally effective and safe care for their illness, and to stimulate research, education and training in palliative care services among medical, nursing, allied health science students and graduates

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
3.1	Further opportunities for research, continuing education and training are identified	Continuing QA activities in teaching and research	Area Palliative Care Service	Ongoing			KC6.1
3.2	Educational and clinical links are strengthened including a weekly clinical forum	Clinical weekly forum established for all staff at relevant sites	Area Palliative Care Service	April 2002			KC7.2
3.3	Professional development gaps are identified and addressed	• Training needs identified • Training reporting mechanism formalised	Area Director Palliative Care / Director Palliative Care Braeside / Area PC Coord	Ongoing			KC6.2
3.4	An Area Palliative Care training rotation approved by the Royal Australian College of Physicians is further developed	• Training rotation in place • Links with College are strengthened	Area Director Palliative Care / Director PC Braeside	• Jan 2001 • Ongoing			KC7.1
3.5	Develop coordinated education programs across the Area to meet PCA standards for all appropriate health care professionals	• Education programs developed and implemented area-wide • Reporting mechanisms put in place	Area Palliative Care Service	• Ongoing • Dec 2002			KC7.2
3.6	Develop an area-wide system for assessing referrals for palliative care patients against agreed criteria	Assessment and referral system developed and implemented area-wide	Area Palliative Care Coord	June 2002			KC5.3
3.7	Review area procedures and guidelines for nursing	• Review complete and gaps identified	A PC Coord /CNCs	March 2003			KC5.3
3.8	Coordinate quality improvement programs and formalise reporting	Reporting mechanism initiated	Area Director Palliative Care / A PC Coord	December 2002			KC5.1
3.9	Long term accommodation needs are assessed and recommendations made	• Needs assessment complete • Recommendations made	Area Palliative Care Service	Dec 2003			KC3.4
3.10	Review psychological needs in the SWSAHS Palliative Care Service	• Analysis of patient, carer and staff needs complete • Recommendations made	Area Director Palliative Care / Project Officers	March 2004	As per proposal	Area Palliative Care budget	KC6.1

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
3.11	Improve communication with Palliative Care Services for patients accessing services in other Area Health Services	Good communication mechanisms in place	Area PC Coord	March 2004			KC3.5
3.12	Develop Service Level Agreements with Sectors for Palliative Care Service provision	• SLAs developed and in place in each Sector	Area Director Palliative Care	September 2002			KC3.5, 4.1, 5.4
3.13	Formalise links with SWAHS Emergency Departments to avoid unnecessary acute admissions	• Links formalised and protocols established • Education gaps identified and training provided	Area Director Palliative Care/ Area Palliative Care Coordinator	June 2002	Priority Health Care Program		KC3.4

GOAL 4: BETTER VALUE

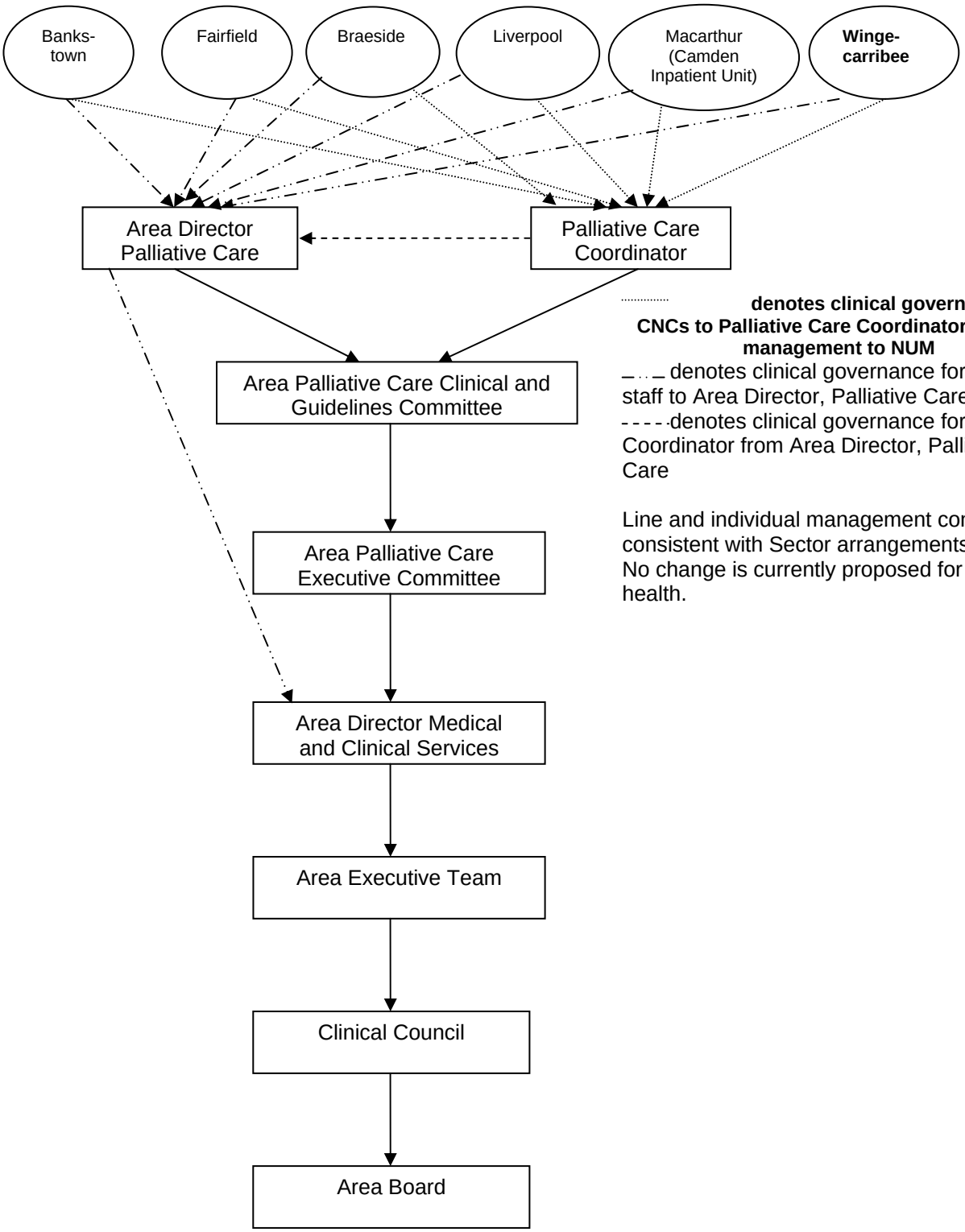
SERVICE OBJECTIVE: To ensure that palliative care services are delivered in the most efficient manner possible

No.	STRATEGY	PERFORMANCE INDICATOR	RESPONSIBILITY	TIME FRAME	RESOURCE REQUIRED	SOURCE	LINK SDS
4.1	That the Area Director's role include responsibility for the management, provision and quality of all palliative care medical staff and all palliative care medical positions be Area positions (with a focus on a particular Sector/s)	• All medical appointments are Area positions • Service level agreements are developed	Area Director Palliative Care / Area Human Resources / GM Hope Health Care / GMs	Sept 2002			KC6.2
4.2	That Palliative Care data be included in the proposed Area Cancer Registry	Palliative Care database is linked to the Area Cancer Registry	Area Director Palliative Care / Data Manager / Area PC Coordinator	June 2002	Data Manager	Chronic Care or budget enhancement	KC2.3
4.3	Identify strategies to improve allied health service provision for palliative care patients	Strategies identified and implemented	Area Director Palliative Care / Area Advisor Allied Health	Feb 2004			KC2.3
4.4	Implement the proposed Area model for Palliative Care Service delivery	• Model implemented • Area Palliative Care Executive Committee in place	Area Director Palliative Care / Area Executive	March 2002			KC2.3
4.5	Review the role of volunteers to maximise effectiveness	Volunteer service reviewed and recommendations implemented	Area Director Palliative Care / Area Volunteer Coord / GM Hope Healthcare	June 2003	Area Volunteer Coordinator position increased to full time	Budget enhancement	KC5.4
4.6	Comply with NSW Health recommendations for SNAP	SNAP data collection implemented	Area Director Palliative Care/ Director Palliative Care, Braeside	Ongoing			KC4.6

Appendix II – SWSAHS Palliative Care Service Structure

SECTOR PALLIATIVE CARE SERVICES

Medical, nursing and allied health staff providing a range of community and inpatient services



denotes clinical governance for CNCs to Palliative Care Coordinator. Line management to NUM

_ . _ denotes clinical governance for medical staff to Area Director, Palliative Care

- - - - - denotes clinical governance for Coordinator from Area Director, Palliative Care

Line and individual management continues consistent with Sector arrangements for staff. No change is currently proposed for allied health.

Appendix III – Palliative Care Staffing

Table 6 – Staff by Sector in the Community

Category	BNK	FRF	LIV	MAC	WGE
Nursing					
CNC	1.0	1.0	1.0	1.0	1.0
RN/CNS	4.6	2.0	1.0	2.0	
Other	2.5	1.4	1.4		
Allied Health					
Physio					
OT					
Social Work	0.6			1.0	
Psychology					
Bereavement		0.5			
Pharmacy					
Other					
Pastoral Care					
Other staff					
Volunteers					

Table 7 –Staff by Sector in Hospitals

Category	BNK	FRF	LIV	MAC	WGE	Brae	Area
Medical Directors / Staff Specialists			0.5	1.0 (shared with Wing'be)		1.5	1.0
Medical Registrars / Clinical Fellows			0.5	0.5		2.5	
Nursing							
NUM				1.0		1.0	
CNC			1.0			1.0	1.0
CNS			1.75			1.0	
RN/EN				13.3			
Allied Health							
Physio				.5		1.2	
OT				.5		1.0	
Social Work				.5		2.0	
Psychology							
Bereavement						1.0	
Diversional Therapy						1.0	
Pastoral Care						1.0	
Other – Speech Path				.5		1.0	
Volunteers Coord.						.5	.5

Notes:

1. Braeside medical staff also cover day hospital, provide community and outpatient consultative service in conjunction with Area director
2. Allied health staff at Braeside provide Day Hospital as well as community and outpatient service in addition to the inpatient service
3. Pharmacy, Pastoral Care, Speech Pathology and Dietetics services at Braeside are hospital-wide services. There is no specific allocation to palliative care
4. All medical positions provide an Area-wide service.

Table 8 – Gleeson Report Benchmarking Information Comparison Palliative Care Data

Health Area	Population and Area	No. of Cancer Deaths per Annum	No. of Designated Palliative Care Beds	Bed Occupancy	Average Length of Stay	Domicilliary Medical Consults	No. of new Medical Referrals	Number of Medical Staff			
								Staff/Spec Consult CMO	Regist/ RMOs	VMOs	TOTAL
CSAHS	450,000	681(*4)	35(*1)	74.6(*1)	18.6(*1)	Yes	901(*2)	4	**7**		11
NSAHS	(*3) 730,000 15% NESB	(*4) 1,335	Greenwich 19 Neringah 40	(*1) 80.4 69.59	(*1) 17.5 17.9	Yes Yes	Data not Collected Data not Collected	1.5 1 1 CMO	1 2	.3FTE .25FTE	12.5
SWSAHS	650.000	(*4) 892	Braeside 20 Camden 7	(*5) 79.8	(*5) 11.1	Yes	(*5) 961	2.50 0.50 (L'pool Hosp Oncology Funds)	2.4 0.5(*6) 0.5(*7)		6.4

**1 NSW Public Hospitals Comparison Data Book 1995/96*
**2 1996/1997*
**3 Northern Sydney Area Health Service Strategic Plan Palliative Care Services 1995-1998 (1991 Census)*
**4 NSW Cancer Registry (1995 figures)*
**5 Statistics collected from November 1996 to November 1997*
**6 Camden*
**7 Temporary*

NSAHS figures do not include the Peninsula service.

REFERENCES

[i] WHO. *World Health Statistics annual 1990.*
[ii] ibid.
[iii] Stjernsward, Jan and Pampallona, Sandra, *Palliative Medicine – A Global Perspective*
[iv] WHO. *Cancer Pain relief and Palliative Care.* Technical Report Series No. 804. Geneva: WHO, 1990.