Palliative Care Strategic Plan for South Western Sydney

Strategic Imperative
Advances in prevention, early detection, diagnosis and treatment of disease, including cancer, are allowing people to survive and live longer. As the number of survivors grows, the demand on health care services will increase, including the need for improved palliative care. Australian data indicates that ageing, the increasing proportion of people expected to suffer and eventually die from chronic progressive illnesses, and the increasing focus on equity of access, appropriateness and location of palliative care will contribute to the need for more, and a greater diversity of, palliative care services.

Palliative care improves the quality of life of patients and their families facing the problem associated with life threatening illnesses. It is not just about dying but living in the most comfortable way with the illness. Palliative care involves not only specialist palliative care services, but also primary care providers and other health and support services in community, residential aged care and hospital settings.

In 2011, 6 out of every 1,000 separations (0.6%) in Australian hospitals were for palliative care and most (94%) were overnight. The average length of stay (ALOS) was 12.5 days, four times longer than the ALOS for all separations. Although commonly thought of as part of cancer management, approximately 40% of palliative care separations nationally (and an estimated 50% locally) are due to other chronic health conditions such as heart disease, COPD, renal failure and dementia. Of note over the last ten years is the ‘real’ increase in the number of admitted patient palliative care separations above which can be explained by population growth and an ageing population. Of note is that 60-70% of people wish to die at home, however the reality nationally and locally is very different from this.

Population projections indicate significant population growth and ageing over the next ten years in South Western Sydney, considerably above the NSW rates. In addition, on a range of indicators the health of local residents is poorer, with higher rates of hospitalisation and premature death. Growing demand for health care associated with population growth and ageing will place increased demands on local health care services, including requirements for more flexible and responsive primary and specialist palliative care. In light of the impact of this demographic shift, planning for a palliative care model and service system response which enables quality end of life for all residents of South Western Sydney is crucial.

The SWSLHD Model of Care requires that “the right services are provided by the right team in the right place at the right time”. Although specialist palliative care services are still developing in South Western Sydney, there is a need to consider how all health services, including primary health care, emergency departments, pain services and chronic care specialities, and the broader support and community system, including residential aged care facilities respond to, care for and support the decisions of patients and their families at this critical stage of life. Fundamental to this model are the principles of equity, quality, dignity and respect and patient and family centred care underpinned by systemic responses of integration, partnerships, capacity and capability.

Policy and Organisational Context
The National Palliative Care Strategy 2010 provides the overarching policy and planning context for palliative care in Australia, covering specialist and generalist/primary health care. The strategy has four goals: awareness and understanding - via an improved appreciation of dying and death as a normal part of the life continuum and enhanced community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services; appropriateness and effectiveness - of care based on need; leadership and governance - which supports collaborative, proactive, effective governance of national palliative care strategies, resources and approaches; and capacity and capability - for all relevant sectors in health and human services. The strategy is...
supported by guidelines targeted on settings of care such as community and aged care facilities, and population groups such as Aboriginal people. 6-8

In addition, national guidance in palliative care practice is provided by Palliative Care Australia through the Standards for Providing Quality Palliative Care for all Australians 9 (2005), which is currently under review, and in planning. 10, 11

The NSW State Health Plan: Towards 2021 12 provides a strategic framework which brings together NSW Health’s existing plans, programs and policies and sets priorities across the system for the delivery of ‘the right care, in the right place, at the right time’. The directions in the plan focus on keeping people healthy, providing world class clinical care and delivering truly integrated care. The NSW Government Plan to increase access to Palliative Care 2012-2016 13 operates within this broad context and sets the NSW agenda for ensuring access to quality palliative care regardless of economic or social circumstances, geographical location or medical condition. The Plan supports new partnerships and linkages between specialist and generalist services to support care provision for dying patients in the community and residential aged care settings. It focuses on four action areas: expanded community based palliative care, especially in rural areas and for special needs populations; integration of primary care, aged care and specialist palliative care services; expanded support for families and carers; and extended capacity of palliative care services in NSW by enhancing existing palliative care services and using and building skills of the multi-disciplinary teams which provide such care.

There has also been a focus on decision making and planning at the end of life, with the NSW Health Advance Planning for Quality Care at End of Life - Action Plan 2013–2018 14 providing direction for implementing advance care planning in the NSW public health system, including strategic partnerships with other government agencies and primary, acute and aged care sectors. The Plan seeks to normalise advance care planning and improve end of life care by integrating patients’ wishes into the management of chronic life-limiting illness. On online resource has also been developed to support clinicians in NSW. 15

These plans have been supported by NSW policy including the Palliative Care Role Delineation Framework 16 which provides consistent and common language to describe and differentiate health care services across NSW; the NSW Paediatric Palliative Care Planning Framework 2011-2014 17 which identifies the existing paediatric palliative care services and opportunities to improve paediatric palliative care in NSW; the Palliative Care Strategic Framework 2010-2013 18 which addresses planning, service standards, data and evidence based practice and requires each health service to develop a palliative care service plan; and the Dementia Services Framework 2010-2015 which includes a focus on palliative care for people with dementia. 19 The NSW Agency of Clinical Innovation is also driving continuous improvement by developing a model for palliative care and end of life, identifying the systemic issues which affect care and supporting local health districts to develop their own, localised models of care. 20-22 A stronger quality focus is also achieved through evaluations such as the Palliative Care Outcomes Collaboration

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Source: World Health Organization 2002. 2

SWSLHD Palliative Care Strategic Plan 2015-2019 – Scoping Paper July 2014
Specialist palliative care needs have been broadly considered in the SWSLHD Strategic & Healthcare Services Plan\(^4\) and the SWSLHD Cancer Services Strategic Priorities Plan; \(^24\) and incorporated into capital planning for Liverpool, Campbelltown and Bankstown-Lidcombe hospitals. Service development consistent with these directions includes the establishment of a new inpatient unit at Liverpool Hospital and the Palliative Extended Aged Care in the Home (PEACH) model which has been implemented in SWSLHD and other local health districts and is currently being evaluated.

In addition a SWSLHD Advanced Care Planning and Care of the Dying Committee has been established to progress implementation of NSW directions regarding advance care planning at a local level through activities such as promotion, training and education and policy development.

Less attention has been given to how the District continues to develop specialist services; how the broader health and support system can work collectively (including specialist palliative care services, primary and community health services, emergency and other specialist services) to best support people with life threatening illnesses and their carers in south western Sydney into the future; the role of the community service sector and local residents (such as relatives, friends and neighbours) in supporting end of life; and how capacity is built. Without these discussions, there is potential for services to incorrectly assume that specialist palliative care will meet all needs, for patients to receive suboptimal care and for the person’s wishes to remain unfulfilled.

**Aim**

To provide a five year Strategic Plan for Palliative Care in SWSLHD, which outlines a future service system model and service directions, including clinical networks and infrastructure required to meet projected demand.

**Auspice of the Plan**

A Steering Committee is proposed to oversight and direct the planning process. The Committee will be jointly chaired by the SWSLHD Clinical Director Cancer Services and SWSLHD Director Clinical Governance. The core members of the Committee could include the SWSLHD Director Cancer Services and representation from specialist Palliative Care leadership, Nursing, Allied Health, General Managers, Consumers, Pharmacy, Emergency Department, Paediatrics and Neonatology, Hammondcare, a residential aged care facility and the South Western Sydney Medicare Local.

**Scope**

The SWSLHD Palliative Care Plan will provide a framework for service development required over the coming five years. The potential structure for the plan is outlined as follows:

- Policy and organisational context at a national and local level including within the not for profit and profit sectors
- Current community profile, including the diversity of the community
- Profile of palliative care patients – cancer and non-cancer related, demographics and activity
- Impact of future demand to 2021
- Profile of current specialist palliative care services, primary and other specialist health services and community supports which meet the needs of people who are dying and their carer/s
- Gaps/deficiencies in the current health and support service system including activity, capacity, partners in care and enablers e.g. workforce, IT, data and research
- A model of palliative care service and support for south western Sydney for the future which:
  - enables a comprehensive, integrated health and community support system involving the patient, their carer/s, primary health care, ED, community health, specialist palliative care, other specialist health services and the broader community
o extends across inpatient, ambulatory, outpatient, community and residential aged care settings
o considers the spectrum of palliative care including early identification, assessment and treatment of physical, psychological, socio-cultural and spiritual needs, active support and care (i.e. health promoting/compassionate communities), and bereavement35

- Critical strategic developments for the immediate future at a District and local government level
- An action plan which includes strategies, actions and timeframes required to progress the model of palliative care service and support, priority service developments, integration and networking arrangements and relationships across the District and with key partners in care (public and private). This will be broadly structured around goals in the National Palliative Care Strategy:
  1. Awareness and Understanding
  2. Appropriateness and Effectiveness
  3. Leadership and Governance
  4. Capacity and Capability
  5. Enablers e.g. infrastructure, Research, etc.

Key Questions to be addressed

- What do patients and their carers and family members require and want to support them?
- What are the concerns of specific population groups, including children (and their parents), Aboriginal people and people from culturally and linguistically diverse communities?
- What is current and future demand?
- What are the gaps and needs in all settings (hospital, aged care facilities and community) in specialist and non-specialist palliative care and support?
- What does an integrated model of palliative care for South Western Sydney look like?
- What action is required to build an integrated system of community support? How can the community be better engaged in supporting people who are dying and their carers?
- What systemic response is required to identify people with palliative care in a timely and supportive manner?
- Where are the areas of knowledge and skill deficit in public, not-for profit and private specialist, non-specialist and other services and how do equip staff and services with the competencies that are needed to support local residents in the community and health facilities?
- What additional support and action is required to ensure support and carer is provided in a culturally and age appropriate manner?
- What are the priorities for action at a District and local level across the spectrum of service delivery?
- What action is required to address gaps in system-wide enablers such as information technology, business intelligence, professional development, teaching and research?
- How is sustainability and ongoing engagement with the broader service system and the community ensured?

Conduct of Planning

A Steering Committee is proposed to oversight and direct the planning process, the potential membership as outlined above. The major steps in planning are as follows.

1. Clinical and Quality Council and Steering Committee endorse the scope. Steering committee membership is confirmed.
2. Prepare and revise background data and information to inform discussion by significant stakeholders.
3. Review outcomes from consultations with patients and their carers, and use this to map out a consultation strategy consistent with SWSLHD Consumer and Community Participation framework. Include consideration of targeted consultations with specific population groups.
4. Develop and undertake a broadly based consultation process with clinicians (GPs, specialists, nurses and allied health) and other service providers in the public, not for profit and private sectors which identifies strengths and gaps/deficiencies in palliative clinical and non-clinical care and support, and areas for future development.
5. Consult with patients, carers/family members, other community stakeholders and the Consumer/Community Council to identify community perceptions of current gaps/deficiencies in healthcare service delivery and priority areas for future development.

6. Stakeholder perceptions summarised into a single paper for consideration by the Steering Committee.

7. Steering Committee considers the information from stakeholders, and identifies key priority areas for action and elements of an integrated model for palliative care.

8. Planning Unit summarises priorities and prepares a summary paper/draft plan which outlines challenges and proposed directions.


10. Finalisation and endorsement of the Plan through governing structures.


**Resourcing Issues**

The majority of this process would be progressed within the in-house resources of the SWSLHD Planning Unit and the SWSLHD Palliative Care Services. A working party will support this process.

**Indicative Process and Timeframes for Consultation**

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Strategies</th>
<th>Indicative Timeframes</th>
</tr>
</thead>
</table>
| 1. Scope project | • Scoping paper developed  
• Scoping Paper considered by the SWSLHD Clinical and Quality Council | August 2014 |
| 2. Consolidate planning process strategy | • Establish and hold the first meeting of the SWSLHD Palliative Care Strategic Plan Committee. Expected outcomes confirmed  
• Consult with the Manager Community Consultation and key CCC members and Director Aboriginal Health about preferred consultation processes  
• Consolidate and confirm detailed planning process and consultation approaches  
• Preliminary consultation with the CCC about potential community issues and concerns | September 2014 |
| 3. Identify current situation | • Summarise achievements in the last 3-5 years  
• Map existing palliative care and other specialist care and support services, networks and relationships  
• Identify and review current and projected activity  
• Review and summarise findings from consultations with patients  
• Identify local responses to NSW Ministry of Health plans  
• Summarise activities/plans of the SWSLHD End of Life Committee | October 2014 |
| 3. Determine scope for change | • In consultation with the Steering Committee, determine/finalise consultation process i.e. in depth interviews, surveys, focus groups and consultation questions and key stakeholders  
• Undertake consultation process – gaps, needs, issues and strategies  
• Summarise outcomes from consultations | October - December 2014 |
| 4. Draft strategic direction | • Steering Committee to review feedback and identify priority areas for action; process for consultation on strategies confirmed  
• Model of integrated service delivery developed and reviewed  
• Areas of strategic action drafted and consolidated | February 2015 |
| 5. Strategic directions consolidated and Plan | • Detailed draft Strategic Plan developed  
• Draft circulated for comment through online surveys, invitations to formally submit comments and meetings with targeted communities and groups to confirm direction | March/April 2015 |
Objectives

Strategies

Indicative Timeframes

7. Finalisation of the Plan

- Steering Committee considers feedback and confirms implications for draft strategies including governance arrangements
- Draft Plan reviewed and finalised
- Strategies costed
- Completion of an Aboriginal Health Impact Assessment

May 2015

8. Approval

- Endorsement by SWSLHD Clinical Council
- Plan finalised, sent to printers for publication
- Formal launch and placed on SWSLHD Webpage
- Plan distributed to key partners, facilities and streams
- Implement governance arrangements for Plan implementation.

July 2015

Preliminary List of Stakeholders

- Patients requiring palliative care including population groups of
  - Adolescents and young adults
  - Babies and Children (paediatrics)
  - Aboriginal people
  - Culturally and linguistically diverse communities
  - People with non-malignant chronic disease
  - People with cancer
  - People who are aged and those with dementia
  - People in rural areas
  - People with HIV/AIDS
  - People with disabilities

- Carer/s and families
- Volunteers
- SWSLHD Palliative Care specialist staff – including physicians, nurses and allied health.
- Other SWSLHD primary and specialist services including
  - Community Health
  - Critical Care (particularly Emergency Department, Intensive Care, Pain Medicine and Anaesthetics)
  - Cancer
  - Aged Care
  - Complex and Chronic Care
  - Paediatrics
  - Other medical and surgical specialties

- Acute and subacute facilities including public, not for profit e.g. Braeside Hospital
- Facility Executive
- Primary Health Care – including the South Western Sydney Medicare Local, general practitioners and community pharmacists
- Residential aged care facilities - including Hammondcare and other providers
- Chaplaincy and pastoral care
- SWSLHD staff - clinicians (e.g. medical, nursing and allied health) and non-clinical staff
- SWSLHD Consumer/Community Council, Networks and the broader community members
- Aboriginal organisations e.g. Tharawal Aboriginal Medical Service, Marumali and Gandangara Local Aboriginal Land Council and SWSLHD Aboriginal health staff. The process will be confirmed as part of the completion of the Aboriginal Health impact assessment
SOUTHWESTERN SYDNEY LOCAL HEALTH DISTRICT

- SWSLHD Enabling Services e.g. Centre for Education and Workforce Development (CEWD), Information Management and Technology Division (IM&TD)
- Community and social service agencies and services e.g. Community transport, Ageing Disability and Homecare
- Peak bodies e.g. NSW Carers Association, Living Caring Working, Palliative Care Australia
- Private providers e.g. Silver Chain Nursing, private hospitals
- Private consortium at Bundanoon
- Ambulance Service of NSW and other NSW local health districts
- NSW Health specialist networks and pillars e.g. Children’s Hospital Network, Health Education and Training Institute (HETI)
- Educational institutions e.g. University of NSW, University of Western Sydney, University of Sydney

References

21. ACI Palliative Care Network, Diagnostic Report to inform the Model for Palliative and End of Life Care Service Provision. NSW Agency for Clinical Innovation: Sydney. 2014.

