SUBMISSION TO THE SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS

INQUIRY INTO PALLIATIVE CARE IN AUSTRALIA

SOUTH AUSTRALIAN GOVERNMENT

March 2012

Introduction

The South Australian Government welcomes the opportunity to make the following submission to the Inquiry into Palliative Care in Australia.

On 23 November 2011, the Senate asked the Senate Standing Committee on Community Affairs to inquire and report on the provision of Palliative Care in Australia and make recommendations on the following matters, including:

1. the factors influencing access to and choice of appropriate palliative care services that meets the needs of the population including those in rural and regional areas, Aboriginal people, individuals from culturally and linguistically diverse backgrounds, people with disabilities and children and adolescents.

2. the funding arrangements, efficient use and effectiveness of various palliative, health and aged care resources.

3. the composition of the palliative care workforce, the adequacy of standards applying to palliative care provision and the availability and funding of research, information and data about palliative care in Australia.

4. advance care planning and national consistent, end-of-life communication between health care professionals and dying patients, national consistency in law and policy supporting advance care directives, and scope for including advance care plans in personal electronic health records.

Key Messages

1. South Australia has the highest proportion of older residents in Australia. In 2011, there were approximately 266 000 people aged over 65 years. By 2021, people aged over 65 are projected to increase by 46.8 per cent and by 2031, 440 000 people (one in five) will be aged over 65. Of these people, 230 000 will be over 75[1].
2. The South Australian Government is committed to enhancing South Australia's palliative care services and end-of-life care with the development of the *Palliative Care Services Plan 2009-2016* (the Plan)[2]. The Plan provides the framework for South Australia's palliative care service delivery program.

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[1] *State of Ageing in South Australia 2010*

[2] South Australian *Palliative Care Services Plan 2009-2016* can be found at website: http://www.sahealth.sa.gov.au/wps/wcm/connect/59c8b100426096b5ba11beb44d317729/palliativecareplan09-16-clincialnetwroks-sahealth.pdf?MOD=AJPERES&CACHEID=59c8b100426096b5ba11beb44d317729

3. The Plan was developed to strategically plan for the most effective utilisation of services, to ensure the sustainability of palliative care services and, in particular, to respond to an ageing population and an ageing health care workforce.
4. Rather than relying on specialist services, which may not be needed in many cases, South Australia is currently restructuring its palliative care services to better meet demand, to promote and increase the capacity of primary care services to provide palliative care, resulting in enhanced integration, sustainability and formalised links and strengthened partnerships between metropolitan and country services.
5. Implementing the Plan in South Australia will mean that people at the end-of-life will be able to receive palliative care or end-of-life care either at home, in a residential care setting or in hospital, with regionalised palliative care services providing integrated services for people in the setting of their choice.
6. The South Australian Government is strongly committed to improving the responsiveness of the health system to support the needs of Aboriginal people, and recognises the importance of culturally-responsive health services, including the need for some Aboriginal people to ‘return to country’ to die.
7. Using a systematic approach to recruitment, retention and role innovation, South Australia is developing and implementing a palliative care workforce strategy to build the capacity and the sustainability of palliative care teams, including the early incorporation of a range of specialist roles including consultant physiotherapists, occupational therapists, pharmacists, clinical psychologists and the caregiver network facilitator.
8. A consistent national approach to clinical care and treatment planning, documentation and communication is needed. Consideration could be given to developing national guidelines for end-of-life care and clinical care planning, particularly for clinicians working in community or primary care.
9. Shared education and strategic research programs will support and enhance the model of palliative care service provision in South Australia.

Addressing the Terms of Reference

The provision of palliative care in Australia, including:

(a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

The South Australian Government has a clear commitment to expanding palliative care services with the development of the South Australian *Palliative Care Services Plan 2009-2016* (the Plan). The Palliative Care Clinical Network has also been established, which is a multi-disciplinary group, providing leadership, strategic direction and guidance to metropolitan and rural regions of the South Australian health service to ensure South Australians are able to access appropriate palliative care and end-of-life care. The Palliative Care Clinical Network's mission is shaped by the goals and outcomes identified in the Plan.

As South Australia's population ages, there will be more people in need of end-of-life care and palliative care services. Therefore, appropriate end-of-life care and palliative care services options should be available and accessible by all who need them.

The strategic and system-wide response outlined in the Plan seeks to address current and future demand. The Plan has a particular focus on improving access to care for all population groups, including those with specific needs, to make it easier for all people at the end-of-life to receive palliative care or end-of-life care either at home, in a residential care setting or in hospital. This will be achieved by implementing regionalised palliative care services to provide an integrated service to care for people in the setting of their choice.

The provision of palliative care is complex and can be assisted by the involvement of allied health care professionals by providing flexible options of care across the professions. Remaining focused on the person/patient/client (and their loved ones) as the centre of care is the key to achieving better outcomes.

The support of general practitioners, possibly through Medicare Locals, to provide home visitation services, prompt referral of patients with complex needs to speciality palliative care services, or to obtain palliative care specialist advice is critical for effective and supportive community care for people at or approaching the end-of-life.

The establishment of Medicare Locals and links with the Local Health Networks in South Australia provide an opportunity to strengthen these services. Increased access to palliative care education is needed for those working in primary care, community care and aged care, including care workers.

i. *People living in rural and regional areas*

Access to palliative care services for those living and dying in rural and remote regions is addressed in the Plan. The service architecture of the Plan provides for expanded clinical services at four South Australian Country General Hospitals (Mount Gambier, Port Lincoln, Berri and Whyalla) and will enhance the capacity to develop end-of-life care services at these sites.

SA Health funds education programs for staff, including general practitioners, in rural regions. However, more could be done in primary care and aged care to support the delivery of care in the community, particularly having timely access to general practitioners and allied health care professionals.

ii. *Indigenous population*

The South Australian Government is committed to improving the responsiveness of the health system to support the needs of Aboriginal people, and recognises the importance of culturally-responsive health services. It is recognised that many Aboriginal people may want to ‘return to country’ to die.

SA Health is supporting Local Health Networks which provide palliative care in-patient services to increase their capacity to support the cultural and spiritual end-of-life care needs of Aboriginal South Australians. The Plan emphasises the need to develop specific palliative care packages to meet the needs of Aboriginal people. South Australia’s services continue to look at ways in which existing links with Aboriginal health services can be improved and strengthened.
The Experience in Palliative Approach Program in South Australia has enabled a number of Aboriginal health workers to undertake placements with palliative care services. The aim is to work with existing Aboriginal services to increase knowledge and awareness of palliative and end-of-life care for Aboriginal South Australians.

iii. *Culturally and linguistically diverse backgrounds*

Palliative care service responses in South Australia are being directed toward collaborative partnerships with community leaders and key workers within culturally and linguistically diverse groups across service catchment areas.
The goal is to build local capacity among local non-government organisations and community groups, through education and training, so that they can provide their own culturally and linguistically specific end-of-life care programs.

Whilst South Australia is expending considerable effort in this regard, it is acknowledged that access to end-of-life and palliative care services for culturally and linguistically diverse background populations is limited, as a result of a lack of awareness and understanding about palliative care. A national public awareness campaign about the issues associated with death and dying, including the benefits of palliative care and end-of-life care at this time, would benefit the culturally and linguistically diverse background population, as well as the general population.

iv. People with disabilities

Improved access and choice for people with disabilities is needed, in particular for those with an intellectual disability, including cognitive impairment, and their carers. Raising community awareness nationally about end-of-life care and palliative care would benefit this population group. South Australia's Disability Services is working with its clients to develop a model of care, including advance care planning.

v. Paediatric Services

The Plan addresses the end-of-life care needs of children, young people and their families, with a particular focus on supporting families to care for the dying child or young person at home, including psycho-social support and bereavement counselling.

The end-of-life care needs of infants, children and adolescents, the needs of their parents, siblings and families are unique, and so too is the palliative care service designed to meet their needs. The South Australian Paediatric Palliative Care Service at the Women's and Children's Health Network is a state-wide service, which includes specialist respite, emergency, palliative and terminal care and sites of care include hospital, hospice or the family home. Bereavement counselling and support is provided through individual home support, in groups and with siblings.

Access to 24 hour telephone support is an essential element of the service to ensure that families have timely access to advice when the need for care is triggered. The volunteer support program ensures families are supported during this time.

SA Health maintains collaborative working arrangements with other agencies and individuals to ensure the continuum of care and support is available to the children and families and that families have choices about care and place of death.

SA Health provides information, expert help and guidance for others involved with the child and family.

(b) Funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

The public provision of palliative care services in South Australia is currently casemix funded. All inpatient activity is funded as sub-acute on the casemix funding model using the diagnostic related group codes. All out of hospital (community) and outpatient activity is currently funded through weighted outpatient occasion of service.

As a result of implementing the Plan, sub-acute funding is now being directed to expand the community based component of palliative care services and is enabling increased numbers of people, if they choose, to remain at home at the end of their life.

Extensive consultation with palliative care services on the needs and priorities for funding in each Local Health Network area ensures that funding is allocated based on areas of need.

(c) The efficient use of palliative, health and aged care resources

The South Australian Plan was developed to strategically plan for the most effective utilisation of services, to ensure the sustainability of palliative care services, particularly responding to an ageing population and an ageing health care workforce.

Implementation of the Plan has resulted in the restructuring and reorienting of palliative care services in South Australia to meet growing demand and to promote and increase the capacity of primary care services to provide palliative care, rather than relying on specialist services, which may not be needed in all cases.

South Australia is committed to a shared care service model that allows for consultation and liaison with palliative care specialists and other appropriate services and community agencies to ensure an efficient and complete person-centred response is provided. Collaboration with community based services, such as the Royal District Nursing Service and general practitioners, is central to the provision of effective services. It is also important that allied health and equipment services are provided in addition to nursing and medical services.

One of the impediments to increasing the capacity of primary health care providers is inadequate funding and staffing to meet increasing demand.
The ability for general practitioners in particular to provide visits to patients at the end of their life in their home or in a residential care facility is currently limited.

In South Australia, Domiciliary Care provides specialist community palliative care for people over the age of 65, with palliative care resources directed toward people with complex physical, psychosocial, and bereavement needs, living in metropolitan Adelaide.

Clear service arrangements between hospitals and community based providers are important. In addition, consistent application of definitions of palliative care/ eligibility between acute/specialist services and home based/community services enables the delivery of seamless quality services. Without this, there is a risk of duplication of services, client confusion and delay in service delivery (including equipment supply).

People with a life-limiting condition and who are discharged from acute treatment services, such as chemotherapy, often require home based community services to restore adequate functionality for daily living tasks, often for extended periods of time. These services are different from end-of-life care services and may be in place for several years. Recognition of the specialist nature of this care is required as distinct from end-of-life (medical/nursing) care that is also required. Typically these services are for people who have longer term decline, with intermittent serious episodes and high levels of prognostic uncertainty.

(d) The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

The design and focus of palliative care services in South Australia is progressively moving toward more seamless operation and influence across settings and sites of care. Specialist services are becoming increasingly deinstitutionalised and regionalised in both their focus and in their corporate identity. This trend has and will continue to see a shift in planning focus toward the population within the service catchment area, in an effort to better understand and respond appropriately to people’s needs.

In South Australia, the aged care setting has been the focus of a number of national and South Australian programs to better address the needs of patients requiring care and for staff providing end-of-life care in these settings.

Access to specialist palliative care services for inpatients requiring admission to a dedicated palliative care unit and a consultation service is provided to all general and clinical specialities in the acute units. It is acknowledged that more people die in the acute care setting than elsewhere, and the support and education for staff providing end-of-life care is a particular emphasis of South Australia’s palliative care services. Not all people at the end of their life require specialist palliative care or hospitalisation. Increasing the capacity of generalist staff to care for those who are dying in all settings, including at home and in residential aged care facilities, is essential for the delivery of high quality end-of-life care and to allow people to die with dignity and in accordance with their wishes.

e) The composition of the palliative care workforce, including

(i) *ability to meet the needs of the ageing population*

The South Australian Government acknowledges that meeting the needs of an ageing population, as the health workforce ages, is a challenge. As a result, SA Health is consolidating its palliative care services into regionalised teams for enhanced integration and sustainability and to formalise and strengthen links and partnerships between metropolitan and country services.

Recasting the balance of end-of-life care that takes place in-hospital and out-of-hospital settings will allow those people who want to, to receive end-of-life care at home or in their residential aged care facility. At the Local Health Network level, supporting residential aged care facilities and developing strong links with Divisions of General Practice/Medicare Locals is critical to building the capacity of generalist providers and the primary and community care sector to increase access to, and the provision of, high quality end-of-life care in a community setting.

Using a systematic approach to recruitment, retention and role innovation, South Australia is developing and implementing a palliative care workforce strategy to build the capacity and the sustainability of palliative care teams, including the early incorporation of a range of specialist roles in services, such as including consultant physiotherapists, occupational therapists, pharmacists, clinical psychologists and the caregiver network facilitator.

SA Health recognises the relevance of advanced practice roles in palliative care with roles in pharmacy, physiotherapy and occupational therapy being built into workforce profiles.

The role of nurse practitioners is recognised as a key element in the provision of expert palliative care with palliative care nurse practitioners identified as a priority development area. A Nurse Practitioner Workforce Development Program is in progress in South Australia to facilitate coordinated training and clinical supervision opportunities across the State.

It is expected that by 2016, Nurse Practitioners will be the most common senior specialist nursing role within palliative care services and will have established a profile across the community, ambulatory and acute care settings.

(ii) *<u>the adequacy of workforce education and training arrangements</u>*

The South Australian Plan has a strong focus on developing workforce capacity, and acknowledges the need for advanced education and training as part of a workforce strategy. South Australia's Palliative Care Clinical Network is integral to the success of this work.

The International Institute of Palliative and Supportive Care is part of the Flinders University of South Australia and offers a range of palliative care post graduate programs. Nurse practitioner courses available in South Australia are the Masters of Nursing (Nurse Practitioner) at Flinders University of South Australia and the Masters of Nursing Science (Nurse Practitioner) at the University of South Australia. Other post graduate programs, including the Masters of Nurse Practitioners, are offered at the University of Adelaide and stand alone subjects, such as Pharmacology for Advanced Practice and Advanced Health Assessment and Nursing Diagnostics, are offered at the University of South Australia.

The SA Health Nurse Practitioner Scholarship and Support Scheme is a South Australian Government initiative aimed at assisting nurses to further their career and priority for this program is accorded to applicants working in palliative care settings.

Access is available to staff requiring training in palliative care at tertiary level, through certificate and short course work. It is a requirement of all staff working in some services to be adequately trained and experienced in palliative care. Access to funding for training and the ability of employing agencies to support staff with funds and time to undertake these courses may be a barrier for uptake in some services. End-of-life care and palliative care education and training for aged care workers and community care staff is critical for good care and should be a mandatory component of all training courses.

(f) The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

The quality of care provided to South Australians at the end-of-life is dependent on many factors, not least of which is a system-wide application and understanding of the common model of care, a degree of consistency in day-to-day use of language, practice and treatment guidelines, outcome assessment and performance improvement strategies. It also hinges on a cultural commitment to teaching and learning and to continuous quality improvement.

The *Standards for Providing Quality Care to All Australians* (the Standards), developed by Palliative Care Australia, provide guidelines which form the basis of measuring and evaluating palliative care services. The application of the Standards through Local Health Networks in South Australia has been ad hoc with some services applying them and others less so. Consideration could be given to an Australia-wide approach to the utilisation and application of the Standards to facilitate a consistent approach to quality improvement and evaluation of services nationally.

Consideration could also be given to mandating the Palliative Care Outcome Collaboration. This would further enable a consistent approach to the ongoing measurement and evaluation of clinical and care outcomes.

(g) Advance care planning, including

(i) *<u>avenues for individuals and carers to communicate with health care professionals about end-of-life care</u>*

In South Australia, there has been an inconsistent approach to decisions and documentation associated with end-of-life care across the public health system, particularly when curative treatment is no longer effective.

A strong national strategy (including education resources) is important to enhance communication about end-of-life care to ensure appropriate access, referral, documentation and provision of end-of-life and palliative care across all care settings.

Clinicians working outside of palliative care have inconsistent knowledge about palliative care, for example when or who to refer to, when to initiate palliative care/end-of-life care discussions or treatment and what this might involve. Clinicians may be uncertain about the timing of such discussions and patients often expect these discussions to be initiated by their health care team. Education and training across generalist and specialties at all levels, about how to have discussions about future care, limits of curative treatment or whether a palliative approach to care is necessary, is warranted.

A consistent national approach to clinical care planning, documentation and communication is also needed. Consideration could be given to developing national guidelines for end-of-life care and clinical care planning, particularly useful for those working in community or primary care, and which can be used within and be transferable across settings for example from acute care to community care.

The South Australian Plan and South Australia's *Health Care Plan 2007-2016* promote widespread uptake of advance care planning through the Informed Choices Program, which helps patients and their families make the right choices for them about future end-of-life care needs and preferences.

A greater emphasis on assisting and educating primary care clinicians about the need for advance care planning discussions would be useful. Often it is too late for advance care planning end-of-life discussions once people are dying, given that at least 50 per cent of people lose their decision-making capacity at the end-of-life. The primary care and community setting is ideally the best time/place for such discussions, which could be undertaken by allied health professionals or nurses, rather than relying on a medical model for advance care planning.

The Palliative Care Council of South Australia Incorporated is a voluntary membership organisation that provides an information resource for consumers and clinicians on palliative care services provided in South Australia and the importance of advance care planning more generally.

(ii) *<u>national consistency in law and policy supporting advance care plans</u>*

The *National Framework for Advance Care Directives* (the Framework) was endorsed by Australian Health Ministers in 2011. The Framework is intended to align Advance Care Directive law, policy and practice across Australia over time. The Framework contains recommended National Terminology, a Code for Ethical Practice and Best Practice Standards for law, policy, forms, guidelines, public and professional information and dispute resolution processes. Adoption of the Framework nationally would assist a nationally consistent approach to advance care directives/plans across all jurisdictions.

(iii) *<u>scope for including advance care plans in personal electronic health records</u>*

Electronic health records will enable better access to health information by health and care practitioners and will mean that people will no longer have to repeat their medical history every time they see a practitioner.

SA Health is proposing the inclusion of Advance Care Directives/advance care plans in its Electronic Patient Administration System (EPAS). Adoption and use of the terms and definitions set out in the National Terminology section of the Framework will ensure consistent and useable information for electronic records nomenclature, both State and National.

(h) The availability and funding of research, information and data about palliative care needs in Australia

The South Australian Government is committed to shared education and research programs that will support and enhance the model of palliative care in South Australia.

The South Australian palliative care community itself generally undertakes the majority of knowledge creation and translation to frame future practice and innovation. Palliative Care Specialist services in South Australia have particular research responsibilities and are expected to deliver purposeful and targeted research programs. In South Australia, the Southern Adelaide Local Health Network conducts the majority of research through its affiliation with the Palliative Care Clinical Studies Collaborative. This work is predominantly grant funded through the National Health and Medical Research Council and the Commonwealth Government.

To ensure sustainability and to secure crucial research link positions, ongoing funding is required. Ongoing funding, rather than a grants process, is more likely to achieve a sustainable and strategic palliative care and end-of-life care research agenda.

A national strategic and collaborative approach to data collection and research, focusing on patient outcomes is needed. The National Health and Medical Research Council may be best placed to undertake this work, particularly with the establishment of Partnerships Centres it has recently announced.