

**Joint submission to the Senate Community Affairs Committees inquiry into
Palliative Care in Australia by the
Clinical Oncological Society of Australia and Cancer Voices Australia
March 2012**

The Clinical Oncological Society of Australia (COSA) is Australia's peak multidisciplinary society for health professionals working in cancer research, treatment, rehabilitation and palliative care with over 1600 members. COSA is recognised as an activist organisation whose views are valued in all aspects of cancer care. We are allied with, and provide high-level clinical advice to Cancer Council Australia.

Cancer Voices Australia (CVA) provides a national, independent voice for people affected by all types of cancer, linking and collaborating with state Cancer Voices in NSW, QLD, VIC, SA and WA. CVA is a respected and integral part of the national cancer control arena, working collaboratively with its member organisations, the Federal Government, State Governments, Cancer Australia, Cancer Councils, COSA, other clinical bodies and key cancer organisations to improve services and care for all people affected by cancer in Australia.

Key Recommendations

COSA and CVA strongly support the formation of a federally-funded national palliative care agency charged with developing Australia's capacity to provide quality palliative care to all Australians in need of palliative care regardless of their life stage and care setting. Despite Palliative Care Australia and the National Palliative Care Program currently performing a number of important functions in palliative care in Australia, we believe that a federally-funded national palliative care agency within government is needed to drive the necessary health services reform required to reduce palliative care disparities and to systematically improve end-of-life care outcomes for patients and their caregivers.

This agency would be responsible for overseeing palliative care standards, funding, access, education and research in Australia by;

- Ensuring that palliative care is on the agenda of all Australian health care organisations.
- Providing and upholding accepted **standards** of palliative care and accountability by organisations that receive funding for palliative care.
- Reducing duplication and promoting better utilisation of existing palliative care resources as well as lobbying government and business for increased **funding** for palliative care.
- **Integrating** palliative care into cancer care services.
- Working across state and territory boundaries to improve **access** to palliative care, linking and coordinating palliative care services in hospitals, hospices, primary care practices, aged care facilities and community agencies providing care at home.
- Promoting the value of palliative care to the community and facilitating **education** of the healthcare workforce in the practice of quality palliative care.
- Providing a portal for palliative care data and the mechanism for collection of this data as well as supporting palliative care **research**.

Additional Recommendations

Integration

- Integration of palliative care as a fundamental part of cancer care including care provision, education, training and research.
- That collaboration between cancer services and palliative care services is supported.
- Implementation of palliative care standards within cancer services.

Standards

- That the standard of palliative care is enforced at a state level through compulsory completion of the National Standards Assessment Program through Palliative Care Australia.
- That the provision of palliative care becomes a compulsory part of the Aged Care Funding Instrument and Residential Aged Care Facility accreditation.
- That the Palliative Care Australia *Standards for providing quality palliative care for all Australians* (4th edition) are revised to provide greater clarity for healthcare providers.
- That guidance is developed for palliative care capability and resource requirements for each type of health service, including residential aged care.

Funding

- A long-term commitment from the Commonwealth to fund programs that have demonstrated their effectiveness in providing palliative care to Australians.
- That a mechanism be established to ensure that the State Area Health Services (or equivalent) are held publically accountable for the funding allocated to palliative care in their jurisdiction.

Access

- That the senate committee revisit the Department of Health and Aging review of Australian paediatric palliative care (2002) to compare its findings with palliative care services currently available to children and young people under the age of 20 years with reference to the NSW Paediatric Palliative Care Planning Framework 2011-2014.
- Expansion of funding to ensure that underserved rural, regional and remote communities (including indigenous Australians) have access to palliative care specialists and psycho-oncologists via recent government tele-health initiatives.
- That incentive is provided through Medicare Locals to promote the establishment of a model of community palliative care that involves general practitioners (GPs) and 24 hour community nurses who express an interest and willingness to train in palliative care.

Education

- Implementation of the Awareness and Understanding goal area of the National Palliative Care Strategy (2010), through a range of initiatives including a national television campaign.
- The expansion of PEPA to ensure all health professionals have access to and incentive to participate in palliative care training relevant to their learning needs and the needs of the population they serve.
- The inclusion of GPs, community nurses and pharmacists in multidisciplinary palliative care teams to provide greater exposure to palliative care protocols and services.
- A substantial investment in education regarding end of life communication skills across all health professions.

Research

- An increased commitment to research implementation to ensure research findings are translated into clinical practice.
- Establishing strategies to monitor and record all types of palliative care activity in Australia.
- An emphasis on palliative care research in health and medical research funding mechanisms within Australia.

Overview

Cancer patients are the largest users of palliative care in Australian hospitals, comprising 60% of all palliative care separations in 2008 - 2009.¹ This submission focuses on palliative care for cancer patients; however the issues and strategies discussed are relevant to other life limiting illnesses. This submission is authored by a working group of cancer care professionals and consumers, representing CVA and over 420 COSA members interested in palliative care.

We believe that for effective palliative care service delivery in Australia, the population based approach advocated by groups such as Palliative Care Australia must be implemented. This approach focuses on the need of all Australians with life limiting illness, an approach that incorporates the entire population once it involves education and end of life planning.² The senate enquiry is a timely one considering that the number of palliative care separations in Australian hospitals increased by 56% between 1999 and 2009,¹ the aging of the Australian population and the corresponding rise in cancer rates.

Factors influencing access to and choice of appropriate palliative care that meets the needs of the population

Access to and choice of appropriate palliative care services by Australians is dependent on a number of factors, including an individual's geographical location, age, cultural background and if care is received in the public or private sector. The limited availability of resources and lack of coordination between services restricts access to palliative care at the population level. Indigenous and culturally and linguistically diverse populations have specific palliative care needs that may not be met by standard palliative care services.³ COSA and CVA have particular concerns for paediatric palliative care patients, palliative care services for regional and rural patients and the lack of support for palliative care services within the community.

Paediatric services

In 2008 – 2009, 0.5% of all palliative care separations were for patients under the age of 24.¹ Young people and their families have specific palliative care needs, primarily the challenges of treatment for grief and bereavement in adolescents and young adults.⁴ In Australia parents prefer to care for their child at home but require financial and practical assistance, especially when treating pain and dealing with the emotional well-being of other children in the family.⁵

In 2002 the Department of Health and Aging funded a review of Australian paediatric palliative care (the *Paediatric Palliative Care Service Model Review*) which found that the needs of dying children had not been addressed within the palliative care system.⁶ It is unclear if these needs have been considered in current palliative care service arrangements. We recommend that the senate committee revisit this review to compare its findings with palliative care services currently available to young people.

The limited distribution of paediatric palliative care facilities outside metropolitan centres is also an issue. One solution provided by the *NSW Paediatric Palliative Care Planning Framework 2011-2014* is the use of "Pop Up" teams to provide palliative care across the state.⁷ These teams, consisting of a GP, a nurse, a specialist and other health care providers would be established around a child and their family for the duration of the child's illness and the family's bereavement.

Rural and regional services

Access to specialist cancer services, including palliative care, is a challenge for the one third of Australians who live in regional and rural areas. Significantly fewer specialists and general practitioners work in rural Australia compared to metropolitan centres.¹³ In 2006 only 22% of regional hospitals administering chemotherapy had a dedicated palliative care doctor and 59% had dedicated palliative care nurses.⁸

The federal government Medical Specialist Outreach Assistance Program is designed to improve access to specialist services in rural and remote Australia. In 2006 a visiting palliative care specialist was flown from Sydney to Wagga Wagga for a day each fortnight and integrated with the local nursing based palliative care team. Over three quarters of referrals to this service were considered appropriate for direct patient contact with a palliative care specialist, indicating the need for and success of this program.⁹

Recent government tele-health initiatives should include access to palliative care specialists as well as psycho-oncologists. The value of access to palliative care specialists by home telemedicine in remote areas has been demonstrated by a number of case studies.¹⁰ Health professionals also need to receive better communication regarding palliative care resources and support available in regional and rural areas.

Due to the lack of palliative care specialists outside metropolitan areas, GPs currently play a pivotal role in the provision of palliative care services in rural and regional areas,¹¹ however many of these GPs do not have the capacity to provide optimal palliative care. This is primarily due to lack of time for training in palliative care,¹⁹ and the inadequacy of palliative care training during undergraduate study.¹² The appropriateness of GPs providing palliative care in rural areas must be questioned as even if further training is provided they may not have the time to attend.

More than 41% of doctors working in rural and remote areas have trained overseas.¹³ Cultural differences that may exist between these doctors and their community are sometimes evident in their approach to palliative care. These health professionals must receive training in the importance of and the provision of palliative care in Australia. This may be provided by the Australian College of Rural and Remote Medicine who already publish palliative care guidelines for their members.

Currently the provision and teaching of palliative care in rural areas frequently depends on palliative care nurse specialists who must advise GPs on pain control. There are reports of GPs refusing to take the advice of these nurses and not using pain control correctly. The National Pain Strategy states:

*At the end of their lives, all Australians will die with their preventable pain and other symptoms well managed, in the place of choice for them and their families.*¹⁴

Training of regional and rural health professionals in pain management is essential for this to occur.

We believe that specialist nurses trained in palliative care are better able to provide palliative care to Australian living in rural areas. These nurses must be supported by local GPs, visiting specialists,¹⁵ and a program of continuing professional development in palliative care.¹⁶

Home and community care

There is a need for both equitable and rapid access to hospital based specialist palliative care, but also for greater support for community services to complement specialist care. Patients with a life

limiting illness eligible to access services through the federal government Home and Community Care (HACC) Program currently face long periods of waiting for care.

Patients unable to access acute palliative care at home are frequently transferred by ambulance to hospitals. On the last day of life for 1071 Western Australians who died between 1 August 2005 and 30 June 2006, 61.5% were in hospital and 4.0% had been seen in emergency departments.¹⁷ This situation is not ideal considering the length of waiting periods and the lack of palliative care expertise in emergency departments. Provision of palliative care in hospitals is not cost effective for both the patient and the health system.

Patients cared for in the community who experience difficulties after hours are in a similar position. Patients requiring a high level of physical care, or who have symptoms that are not well controlled, can only access care via acute services in hospital if consultants are not available after hours.

Recently a man with advanced pancreatic cancer who wanted to die at home became breathless during the night. His wife gave him a sedative and some morphine which was prescribed by his doctor. When this didn't work she phoned the hospice but as there was no bed available he was transferred to the local acute hospital. There the staff had no experience with syringe drivers and the care was kind but not experienced. He died 14 hours later. His wife felt frustrated and defeated after what was a very isolated, frightening and lonely experience.¹⁸

The solution to this problem is an after-hours nurse or respite carer for all community palliative care services.¹⁹ If a nurse had been able to visit the house to give this woman the confidence to continue care at home, the patients wish to die at home would have been fulfilled. A 24-hour palliative care nurse or respite carer able to make home visits would provide the extra support and expertise needed to keep the patient comfortable at home as well as giving the family a sense of control during the final stages of the person's life. This approach would also lead to major cost savings by preventing ambulance use and admissions to emergency departments for palliative care.²⁰

Public awareness

There is very little discussion in the community about end of life issues. Public perception of the role of palliative care and the lack of knowledge of the type of care available limits access to appropriate care for Australians with life-limiting illness.²¹ Patients, their families and health professionals require education to promote the understanding of the breadth of care provided by palliative care services and the times at which palliative care may be accessed.²² Timely access to palliative care services will improve the patient's quality of life and maximise the benefits of care for families and the community.²³

We recommend implementation of the Awareness and Understanding goal area of the National Palliative Care Strategy (2010), in particular goal 2:

To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.

An awareness campaign featuring a well-known Australian talking about palliative care could be the first step.

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

In the 2008 - 09 financial year \$168 million was spent on palliative care in Australian hospitals. The majority of this was in the public hospital system,²⁴ where the bulk of palliative care separations occur.¹ The cost of palliative care also falls on the community; carers may have to give up work, palliative care medications remain expensive despite access to the pharmaceutical benefits scheme and the community must pick up the cost of care when government-funded care is unavailable.

Funding provided by the Australian Government to states and territories for the enhancement of sub-acute care services (including palliative care) under the Coalition of Australia Governments (COAG) has not seen an improvement in State-based funding for palliative care. Distribution of funds for palliative care by state and federal governments must be transparent and based on the needs of the community. Budget items for palliative care are often re-allocated to other sub-acute services that are given a higher priority.²⁵ State Area Health Services (or equivalent) must be held accountable for the funding allocated to palliative care by COAG.

The Federal Government's National Health Reform brings with it the opportunity to restructure the funding and provision of palliative care in Australia. The current model of funding and service provision is fragmented, resulting in gaps between community-based care, hospice care and hospital services. A national palliative care funding and regulatory body could link care in the community and hospices to hospital based care through integration with cancer services, Medicare Locals, the National Health and Hospitals Network as well as supporting rural and remote communities through Regional Cancer Centres.

The efficient use of palliative, health and aged care resources

Greater coordination between palliative care, health and aged care resources is necessary if all Australians are to have equitable access to quality palliative care. The fragmentation of federal and state funding and regulation is inhibiting this coordination. Cancer Voices NSW (CVN) highlights the challenges for patients accessing palliative care in their position statement on care coordination towards end of life:

CVN has heard from several members who are very concerned about the lack of coordinated treatment and care when they become seriously ill or immobilised as a result of their cancer. The cancer care centre and its specialists are no longer the "managing agent" and an unexpected and confusing journey between hospital, rehab facility, home, palliative care, ICU and back again may begin. A characteristic of the problem is poor communications between facilities, specialists and the person's GP and family/carers.²⁶

Acute palliative care facilities, usually based in hospices, must communicate with and support community-based resources. GPs and clinicians in the acute care sector and community-based agencies require systems to be established to ensure seamless care transition and clinical handover. This will decrease the number of patients who experience a gap in their care, improving quality of life for patients and support for their families and improve the efficiency of care.

We strongly support the formation of a federally-funded national palliative care agency charged with developing Australia's capacity to provide quality palliative care to Australians in need of care at any stage of their life. This agency would;

- Work across state boundaries, linking palliative care services in hospitals, cancer services, primary care practices, aged care facilities and care in the community agencies.
- Promote the value of palliative care to the community and ensure that palliative care is on the agenda of Australian health care organisations.
- Be responsible for providing and upholding standards of care and accountability by agencies receiving funding for palliative care.

Palliative Care Australia and the National Palliative Care Program already perform a number of these functions, however an agency within government that is responsible for improving palliative care outcomes would be better able to link existing resources and implement change. The framework for palliative care service planning developed by Palliative Care Australia and outlined in *A Guide to Palliative Care Service Development: A population based approach* is an ideal needs and population based model for a national palliative care organisation to work from.²

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

As the Australian population ages the number of people living with end-stage chronic conditions will increase. GPs are seen by government as pivotal to linking palliative care between specialists and care in the community.²⁷ This reliance on GPs for palliative care in the community is not working due to the lack of priority given to palliative care training in general practice, the lack of knowledge of palliative care planning resources and the constraints of time for busy GPs.³² We believe the provision of palliative care by GPs must be supported by nurses, pharmacists and counsellors who specialise in palliative care in the community. The provision of at-home palliative care respite services delivered by enrolled nurses in the UK has reduced hospitalisation of palliative patients by 80%.²⁸

If GPs are to provide adequate palliative care within the community they must receive education in quality palliative care as well as financial incentives for their time spent on palliative care training. GPs must be made aware of palliative care resources, including the GP section of the CareSearch website that has been specifically developed to provide training and advice for GPs on palliative care in the community.²⁹ Access to specialist advice would also improve the ability of GPs to provide palliative care.

GPs may feel unable to provide the psychosocial care needed by patients and their families.²⁹ Younger GPs and those from overseas are less likely to provide palliative care, reflecting these concerns.³⁰ Use of *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions*³¹ developed by the National Health and Medical Research Council (NHMRC) in 2011 may assist the education of health professionals in the ethics of treating patients near the end of their life.

The reliance on GPs for palliative care becomes a major issue outside of normal working hours.³² The emerging pattern of GPs being unavailable for home and aged care facility visits becomes a serious problem as the patient's illness advances to the point where attendance at a surgery is no longer physically possible. Provision of 24 hour specialist palliative care nurses and training of aged care nurses in palliative care would alleviate these problems. The inclusion of GPs³³, pharmacists³⁴ and nurses in multidisciplinary palliative care teams would also improve communication and provide

further exposure to palliative care protocols and services for these community based health professionals.

The composition of the palliative care workforce, including its ability to meet the needs of the ageing population, and the adequacy of workforce education and training arrangements

The palliative care workforce is inclusive of staff specialists, general practitioners, nurses, allied health professionals and trained carers, family members, pastoral carers and volunteers. In cancer care these professionals include paediatric and geriatric oncologists and nurses trained in the provision of chemotherapy. Palliative Care Australia has outlined the clinical staffing requirement for provision of palliative care services in the *Palliative Care Service Provision in Australia: A Planning Guide*.³⁵ We recommend that these guidelines be applied at the national, state and territory, regional and local levels. The NSW Health *Palliative Care Role Delineation Framework* would also inform this process.²⁷

The Australian & New Zealand Society of Palliative Medicine (ANZPSM) recommends the ratio of one palliative care specialist per 100,000 people and has calculated that currently there may be half that number of specialists in Australia.³⁶ The ANZPSM *Workforce Strategy: Meeting the Palliative Medical Needs of Patients in Australia 2011-2015 and beyond* outlines strategies to combat this and other workforce deficiencies in palliative care in Australia.³⁶

There are significant unmet needs in the palliative care workforce and the wider community of informal carers. These include a lack of palliative care training and knowledge of services and resources as well as pressure on staff providing cancer treatments to also provide palliative care. We support the *National Health Workforce Innovation and Reform Strategic Framework for Action 2011–2015* which states:

A major shift is required towards inter-professional education and practice, where health professionals from different backgrounds learn with, from and about one another to improve collaborative team-based practice and the quality of care delivered.

An emphasis must be made on palliative care training for all health professionals. Continued funding and support for all palliative care providers will distribute care more effectively throughout the community.

Initiatives such as the Palliative Care Curriculum for Undergraduates project and the national Program of Experience in the Palliative Approach (PEPA) have been successful in integrating palliative care into the university curriculum and workplace training. Demand for PEPA has been high, demonstrating the desire of health professionals to learn about palliative care,³⁷ however the specialist services providing the training are not funded for the extra work involved. The sustainability of successful initiatives such as PEPA is integral to building the palliative care capacity of Australia's health workforce.

PEPA offers GPs two or three days training in palliative medicine with a specialist team. In return they are paid approximately \$1,000 per day. Participating GPs report great satisfaction and greater interest in palliative care following their placement.³⁸ However, only 493 GPs³⁹ (of the 18 000 who are members of the Royal Australian College of General Practitioners) have participated in PEPA since its inception in 2003. The main problem is with the current nature of general practice as there

are numerous demands on the study time available to GPs. Many GPs are unlikely to have more than two or three dying patients a year and may be more motivated to take up clinics in subjects they will use more frequently.

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

We would like to make a number of comments regarding national standards for palliative care:

- Standards need to be enforced at a state level by compulsory completion of the National Standards Assessment Program, administered through Palliative Care Australia or delegated national body.
- There must be incentives for standards to be reached. These could include accreditation of facilities and community services once certain criteria have been satisfied.
- Palliative care standards must become part of the standard of care in cancer services.
- There needs to be agreement between palliative care standards and residential aged care standards. We suggest that the provision of palliative care becomes a compulsory part of the Aged Care Funding Instrument and Residential Aged Care Facility accreditation.
- The Palliative Care Australia *Standards for providing quality palliative care for all Australians* (4th edition) are unnecessarily wordy, and need to be clearer for administrators in order for the standards to be implemented.
- Guidance must be clear about the capability and resources required for each type of health service, including residential aged care. Standards that clearly define the minimum number and type of palliative care professionals per capita are required. We recommend adoption of the staff numbers outlined in Palliative Care Australia's *Palliative Care Service Provision in Australia: A Planning Guide*.³⁵

Advance care planning, including avenues for individuals and carers to communicate with health care professionals about end-of-life care, national consistency in law and policy supporting advance care plans, and scope for including advance care plans in personal electronic health records

We support the availability of advanced care planning (especially end of life directives) however we believe the key deficiency at present is the number of clinicians who are highly skilled in discussing these issues with patients, and continuing these conversations as circumstances change. There needs to be substantive investment across all health professionals in education regarding end of life communication skills. Participation in education schemes should be a requirement for continuous practice improvement and accreditation. The *Draft Advance Planning for Quality Care at End of Life: Strategic and Implementation Framework (NSW Health)* states

*...health professionals see that management of chronic life-limiting illness needs to more explicitly and comprehensively address end of life concerns. Furthermore, that the way to ensure end of life decisions are appropriately made is to start advance planning much earlier in the trajectory of these illnesses than currently occurs.*⁴⁰

Electronic records of advanced care plans and end of life directives will not be sufficient in isolation as it is often challenging for health professionals to ensure advanced care directives are followed. Reliance on electronic records may lead to patient wishes being ignored if it is without the

involvement of health care professionals who can provide a continuity of communication, not just a snapshot in time.

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

We would like to make a number of comments about the availability and funding of research, information and data about palliative care needs in Australia:

- There needs to be a commitment to research implementation to ensure research findings are translated into practice. There have been some excellent projects within Australia which have now ceased due to lack of funding continuity or an implementation strategy.
- The needs to be a long-term commitment from the Commonwealth to fund programs that have demonstrated their effectiveness including: CareSearch, Palliative Care Curriculum for Undergraduates project, Program of Experience in the Palliative Approach and the Palliative Care Clinical Studies Collaborative.
- The effectiveness of national standards and guidelines must be evaluated through research to determine their effectiveness and to update and improve practice.
- There is a distinct lack of data available on palliative care in Australia. Data on palliative care based on hospital separations is collected by the Australian Institute for Health and Welfare; however there is little data on palliative care in the community or the palliative care workforce in Australia. Strategies must be put in place to monitor all types of palliative care activity in Australia, perhaps through general practices where referral may occur.

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