Palliative Care in Australia Senate Enquiry March 2012

Submission from: Palliative and Supportive Care, Capital Region Cancer Service ACT Health Directorate

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This submission is in response to Palliative Care needs in a Tertiary Acute Care setting and how this setting interfaces with external service providers and the community.

Provision of Specialist Palliative Care in the ACT

A division of Palliative Care Specialist services exist in the Australian Capital Territory. These services are delivered by two different healthcare entities, Calvary Healthcare ACT and ACT Health. Calvary Healthcare ACT operates the Clare Holland House Hospice and offers inpatient palliative care consultation at Calvary Hospital. ACT Health provides community palliative care coverage (Home Based Palliative Care or HBPC) to patients in their homes and to residents of Aged Care Facilities, with offices located in the Clare Holland House. In addition there is a Specialist Palliative Care consultation team, under the aegis of the Capital Region Cancer Stream, with offices at the Canberra Hospital. Unfortunately this structure creates challenges for the consistency in the level of care provided to patient's dependant on where they access the system.

Recommendation: Single governance organization for territory-wide continuity of care, and more efficient service provision and budget utilisation.

Palliative Care Nurse Practitioners (PCNP's) in the Australian Capital Territory

PCNP's in the ACT are currently bound by State legislation that restricts the ability to work to their full scope of practice. The ACT has not signed onto the pharmaceutical component of the health reform. This prevents Palliative Care Nurse Practitioners in the ACT from writing PBS scripts for pain and symptom relief for patients assessed in out patient settings of hospital. For example: a Palliative Care Nurse Practitioners assesses a patient while they are receiving chemotherapy as an outpatient. The Nurse Practitioner would like to prescribe a PBS script for morphine. The Nurse Practitioner is not able to do this in the ACT or NSW but could if they were working in any other State in Australia. The effect this has is longer waiting times for patients who have to wait for a doctor to write the script. This is not optimal practice for the hospital avoidance model of care.

Recommendation: It would be useful to contact the Australia College of Nurse Practitioners about this issue as they are working with the government to enable Nurse Practitioners to work to their full scope of practice.

Access to Palliative Care Medicines in the Australian Capital Territory

The National Prescribing Service report (2010:43) Achieving quality use of medicines in the community for palliative and end of life care stated that

"The 'system' is currently overly complex for palliative care patients and their health professionals. The process needs to be simpler, easier to apply and more efficient for both patients and health professionals in, for example, accessing specialist and support services, accessing medications, and escalating care when required. Several suggestions have been proposed to improve aspects of the system."

There is state legislation in the ACT that requires prescribers to obtain a CHO number for whom they prescribe opioids. This is in accordance with the Medicines, Poisons and Therapeutic Goods Act 2008(MPTG) prescribers of opioid medications need to apply for approval through the Chief Health Officer. This is time consuming and has prevented some terminally ill patients accessing appropriate medication for a period of time. Discharge medications for patients that are dying are very difficult to obtain. Patients who come into the Emergency Department from a nursing home, then to be transferred back to the Nursing Home for End of Life Care are unable to access initial medications. This can put a lot of unnecessary pressure on the Nursing Home to get medications from a community pharmacist ensuring timely relief from suffering.

It is very difficult to get outpatient scripts filled at the inpatient pharmacy as this does not meet hospital protocol.

Recommendations:

1. Increased access to pain relief for patients in oncology/radiation outpatient settings and other outpatient settings including haemodialysis

2. Access to Palliative Care in the Emergency Department of Acute Care Hospitals

3. Access to essential Palliative Care Discharge Medications for patients returning home (including Residential Aged Care Facilities) from the Emergency Department for End of life Care

4. Special consideration to bypass the CHO number for Palliative Care Patients who have longer than two months to live

5. Funding for non PBS palliative care medications. For example Cyclizine and Gabapentin

Respite

Carer stress and fatigue when caring for a loved one at home, can result in admission to an acute care facility or palliative care inpatient unit. Respite, whether it is in home or provided externally, needs to be available to prevent carer stress. In the ACT if a patient has a carer they can get emergency respite through Carers ACT. If a person lives alone this service is not offered.

Recommendation: Funding for Palliative Care Respite beds and in home respite.

Effectiveness of Hospital Care

End-of Life Care Pathways (EOL Pathways) and Palliative Care Referral Pathways are part of the Department of Health and Aging (DoHA) National Palliative Care Strategy 2010. Emphatic support for funding implementation of the DoHA strategy by this inquiry would be one of the most significant outcomes that could be achieved.

The Australian Council on Healthcare Standards (EQUIP5) fails to provide specific criteria to support and safeguard palliative care service delivery in their quality standards for hospitals. Recognizing the clinical, fiscal and ethical imperatives for considerate goal-oriented and patient-centred healthcare in our aging population, it seems prudent for more explicit identification of the elements required for quality palliative care service delivery by this peak body for quality indicators of hospital based services.

Recommendations:

1. Funding support to implement the DoHA strategy
2. Specific criteria within EQUIP5 Palliative Care Standard

The Deteriorating Patient

Earlier recognition of a palliative care (PC) patient is a significant deficit in the acute care setting. The first identification of a patient who should be considered for palliative care (PC) consultation is often in the circumstance of a MET call (Medical Emergency Team) or on referral to the ICU. Not only does the current process not identify these patients before a crisis point, but the actual event exposes these patients to significant risk of invasive (and expensive) management, which promotes treatment related morbidity and extended hospital stays.

Consideration should be given to implementation of triggers for palliative care assessment, similar to the patient centred ICU movement. http://www.medscape.org/viewarticle/551738 In addition, the MET call service should be able to make a PC referral for those patients not likely to benefit from invasive or ICU management. As it stands now, these patients often receive yet a second or even third MET call before shared decision making occurs and goals of care are discussed.

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Bereavement services in the acute care setting

Bereavement follow-up is a core domain for palliative care services. Best practice is to let all next-of-kin know of services available and then to offer counselling to those who come forward for help. This requires an organised system of follow-up; communication between disparate agencies including self-help groups and the ability to respond appropriately to those who request help.

Bereaved people are at greater risk of both physical and mental health problems. About 10% of the bereaved ask for professional help and some of those are depressed, isolated and at risk of not caring for themselves or their children. A typical initial bereavement interview takes 2 hours. This is skilled work as it's necessary to be able to tell the difference between depression, normal grief, complicated grief and demoralisation.

The area is vastly underfunded and social workers, see the bereaved on top of their normal load of supporting the dying and their families. Many parts of Australia have a bereavement service that's separate from Health. Best practice in this area is to have a bereavement co-ordinator. This person could offer public education about normal grief as help as support/co-ordinate health professionals in their role as therapists.

Recommendation: In order to meet Accreditation and National Palliative Care Standards, our service is required to provide information about bereavement services and normal grief to all carers.

Mental health and palliative care

The closer you are to death the more likely you are to be clinically depressed. This depression is under-diagnosed by all health professionals and even dismissed as 'normal in the circumstances'. Depression is a treatable symptom; we are improving in the use of relevant drugs but also in our understanding that sociability, exercise, information, choices and psychological therapies can all assist with depression.

Likewise, as much as 40% of carers of palliative care patients have anxiety disorders. (Peter L Hudson et al, Journal of Pain and Symptom Management 3/3/2011) Again, with resources, we can help with this. Families need information, reassurance, practical advice and sometimes money. Their anxiety concerns all areas of their life current life and future life.

Palliative Care is committed to holistic care and to seeing the family as the unit of care. At the moment there are many gaps in this area of need. Psycho-social professionals are a key part of the team; we need social workers, psychologists and psychiatrists who are in networks such that they can see each others stats, meet regularly to discuss patients and families and also discuss advances in practice. Currently health silos present barriers to ensuring continuity of care.

Health silos work directly against this and make it extremely difficult to practice continuity of care.

Recommendations:

1. Access to psychiatry/psychology for patients and families with mental health needs

2. Clinical supervision for all members of the Palliative Care Interdisciplinary team

3. Use a validated depression assessment tool across the Palliative Care population

ACAT issues for hospital based social work services:

Aged Care Assessment (ACAT) assessments are difficult to obtain for patients with advanced cancer and who are under the age of seventy years (70) and do not have an ‘aged related illness i.e. dementia, stroke, and severe arthritis’. Unfortunately ‘cancer alone’ does not define the need for an ACAT assessment. ACAT request documentation regarding;

(1) What community based services have been trialed or attempted and;

(2) Evidence of this having failed before progression to an ACAT referral being accepted.

ACAT also advise that the community-based nursing home is an aged residential care facility and it is not an appropriate hospital discharge destination. There are difficulties with ACAT referrals when the family/careers are no longer able to sustain the high level of in-home care provisions and the hospitals are no longer providing curative or acute care. Often in theses cases the patient with advanced cancer and their family/carers are left with the only options of trialing community based services with a view to potential ‘failure’ which will most likely result in another hospital re-admission and possibly, a nursing home placement (if ACAT have accepted the referral).

Additionally, application to the aged care facilities requires considerable lead up time for financial assessments; often with large financial deposits and in some cases this requires the sale of the family home. All of this takes considerable time and in the case of advanced end stage care; all of this may be futile with the patient dying in the hospital before a placement offer is made. Patients with advanced cancer require step down facilities that can provide high levels of nursing care and also a high level of terminal care when this is needed. The patient who has a life limiting illness requires care that is suitable for their medical and physical needs and they are unable to cope with the additional pressure of being a hospital ‘bed-blocker’ or an inappropriately placed resident in an aged care facility.

This is an issue that comes up when a patient is deemed to have months to live and is dependant on nursing care. They are not regarded as suitable for hospital or hospice as they will live too long a time; they are not regarded as suitable for Nursing Homes as they will live too short a time. Their care needs are usually too high to be cared for at home. The emotional toll on the patient and his/her family is very high leading to feelings of guilt, anger and sadness. It often happens that the families waste these valuable few months organising assessments and dealing with bureaucracies instead of spending quality time with the person they all know has a prognosis of months.

Recommendations:

1**.** Increased flexibility for Palliative Care Patients needing ACAT and Nursing home Placement