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Mr Peter Dowling MP

Member for Redlands Chair, Health and Community Services Committee hcsc@parliament.gld.gov.au

Monday 6 August 2012

Submission to the Palliative care services and home and community care services inquiry

Dear Mr Dowling,

Thank you for the opportunity to contribute to the Health and Community Services Committee's inquiry into palliative care services and home and community care services.

The pattern of disease, dving and death has changed dramatically in Australia over the last century, with more serious life limiting chronic conditions such as dementia, cardiovascular and respiratory diseases and cancers increasing. Individuals living with these conditions typically experience a disease trajectory characterised by slow progression of disease, often accompanied by acute and unpredictable exacerbations of clinical problems.² Of the 144,000 people who die annually in Australia, the proportion whose death is expected is as much as 50% or 72,000 people. These individuals often live with one or more chronic life limiting conditions for several years. As the population ages, the costs of dying will result in substantial pressure on health expenditure.

The World Health Organisation defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problems 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.⁵ Palliative care services target the period of a life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.³ Palliative care services are provided across the health and human services sector by public and private hospitals, general practitioners, disability services and in residential and community based settings. New approaches to service provision at end of life are required that will be responsive to patterns of disease progression which are extended and unpredictable.1

The policy context for end of life services in most jurisdictions in Australia emphasises integrated and needs-based access to services that have capabilities and resources appropriate to the level of care provided. However, palliative care service provision to date has developed in an ad-hoc manner and there is a growing understanding of the variations in access to and quality of available services.^{6,7} There is also an absence of evidence to support the implementation of needs-based consumer-centred services. With the proportion of Australians aged over 70 years projected to increase from 9% in 2012 to 20% in 2051, demand for palliative care services is expected to increase significantly. As demand for palliative care increases, it is critical that resources are allocated efficiently while maintaining high-quality and effective outcomes.

COMMENTARY ON THE COMMITTEE'S TERMS OF REFERENCE

The capacity and future needs of these services (including child and adolescent palliative care)

Palliative and Supportive Care Service Capacity in Queensland

The QUT Palliative Care Research Group recently undertook a scoping study, commissioned by Queensland Health, investigating palliative care services in Queensland. This report has not been made publicly available and as such, no specific data derived from this study are included in this submission. We have prepared the following summary of the state of palliative care services in Queensland based on records maintained by our group for the purposes of supporting Statewide research, quality and education programs.

Palliative Care Palliative care services and specialist palliative care providers (medical and nursing) are distributed throughout most Health Service Districts in Queensland. There are approximately 38 specialist palliative care

services currently operating in Queensland which can be classified as Level 1-3 according to the Palliative Care Australia Resource and Capability Framework (Appendix 1). In addition there are numerous domiciliary nursing services, GP services and residential aged care facilities which provide palliative care services. The majority of services provide a direct care or shared care approach, with around two-thirds of services providing consultation/liaison services, and some services providing consultation only. To the best of our knowledge, no formal evaluation has been undertaken to confirm the level of these services according to the Queensland Health Service Capability Framework. Moreover, the extent to which the various levels of service providers have adequate linkages to ensure access to higher level services when needed is variable.

In summary, the distribution of services of varying levels of capability and resource is to some extent broadly consistent with the principles of a needs based service delivery model, whereby more comprehensive services are based in large population centres. However, the absence of an overarching coordinated approach to palliative care service planning has resulted in significant variations in service capabilities and resources across the State. The distribution of palliative cares services also suggests that there are challenges for some regions in accessing the level of palliative care services required.

Planning for palliative care services is also hampered by the lack of quality data. For example, data on designated palliative care beds in Queensland are not recorded or reported in a consistent manner and as such is it difficult to accurately assess the availability and adequacy of palliative care services within specific communities or regions in the absence of prospective analysis. A more detailed and specialised analysis of workforce projections is also required to facilitate for future planning for palliative care services.

Future Palliative Care Service Needs in Queensland

Future palliative care service needs in Queensland will be impacted by demographic transitions, policy reform and changes to the Australian healthcare landscape. Key future issues which are likely to impact upon palliative care in Queensland include:

- The implementation of the National Health Reform Agenda with its focus on reducing pressure on acute care services through transition to sub-acute and community based models of care. The creation of 17 Local Health and Hospitals Networks in Queensland through this process offers opportunities for Queensland Health to define new models of care which meet the State's health objectives.
- Demographic shift in the Australian population which will significantly increase the proportion of the Australian population aged over 65 years. This shift is accompanied by changing disease profiles whereby people live for extended periods of time with one or more chronic conditions that are eventually fatal. The shift will increase demand for palliative care services and novel models of care will need to be trialled and evaluated to determine the best approaches to ensuring access to the right service at the right time, and to avoid unnecessary or futile service provision. Traditional models of palliative care, which have developed from an understanding of the needs of people with cancer, will need to be adapted to ensure relevance to the needs of people with a range of chronic life-limiting conditions, comorbidities and frailty.
- Increasing workforce shortages and the ageing of the palliative care workforce will place further pressure on service delivery. Residential aged care is the ninth largest employer in Australia, employing 260,000 in 2007 and accounting for 2.7 percent of the total Australian workforce. The average age of health professionals in Australia is 45.6 years for medical professionals and 44.3 years for nurses, and labour supply is expected to grow at a slower rate than population growth. Over 50% of the palliative care workforce is estimated to be aged over 45 years of age suggesting increased rates of retirement in the coming decades. Innovative education programs are required to develop and maintain the palliative care skills of the generalist and specialist health workforce.
- The shift toward patient centred care is associated with an increasing desire amongst community members to be involved in decision making about their healthcare and to have choices about where their care is provided, including palliative care. This trend will require collaborative engagement between government and nongovernment and health and human services to develop and trial new models for the provision of palliative care.

The Centre for Palliative Care Research and Education (CPCRE) is ideally positioned to play a leadership role in education and research activities which align with national and state-based priorities in palliative care and that focus on the needs of the population. The CPCRE has potential to serve as a coordinating hub that supports relevant organisations and stakeholder groups in Queensland to undertake and contribute to high-quality palliative care education and research activities while protecting the interests and identities of individual collaborators. Key future directions for the CPCRE may include:

- 1. Delivering a systematic program of evidence-based education in palliative care with a focus on supporting the achievement of required competencies/capabilities for the generalist and specialist workforce and thereby building palliative care capacity in Queensland.
- 2. Leading an innovative research program in palliative care, comprising large program grants and smaller pilot projects, with the aim of identifying and testing solutions to address identified challenges and areas of unmet need in palliative care, with the goal of making significant improvements in palliative care delivery and patient outcomes in Queensland. Key areas requiring future research include:
 - Systematic documentation of the care pathways and patterns of care experienced by key population groups at the end of life, especially those with chronic, non-malignant conditions

- Identification of the minimum service components required for the delivery of optimal end of life services to address population needs.
- Evaluation of novel service models and interventions designed to improve outcomes for people at end of life
- Modeling of evidence based changes to existing practice to improve the organisation of palliative care services
- Development of knowledge and resources to guide consumers and health care providers about treatment and use of health resources at end of life
- Develop the evidence base to support health systems, organisations and health professionals to develop
 policies and make decisions about use of health resources at end of life.
- Strengthening infrastructure to support the delivery of high-quality palliative care education and research
 programs for Queensland. This includes supporting the coordination of clinical trials and health service
 evaluations of new interventions and service models across the State, and facilitating the adoption of emerging
 evidence based practices.

The effectiveness, efficiency and adequacy of palliative, frail and chronic care services

Australia is an international leader in the monitoring and evaluation of the quality, efficiency and adequacy of palliative care services. The Palliative Care Outcomes Collaborative (PCOC) was established in 2005 and is funded by the Australian Government's National Palliative Care Program as the only national voluntary program utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. PCOC is led by four centres: the Australian Health Services Research Institute (University of Wollongong – Lead Site); Cancer and Palliative Care Research and Evaluation Unit (University of Western Australia); Palliative and Supportive Services Department (Flinders University); and the Institute of Health and Biomedical Innovation (Queensland University of Technology). The PCOC now collects clinical outcome data from services representing over 80% of all patients seen by specialist palliative care services across Australia. A summary of services participating in the PCOC as at December 2011 is provided at Table 1. This dataset provides a unique and highly valuable resource which enables the benchmarking of services across Australia and within Queensland. The program is supported by PCOC Quality Improvement Facilitators who work with individual services to improve quality.

Table 1 Palliative Care Outcomes Collaborative Data Collection December 2011

State/Territory	Services collecting - Dec 2011	Number agreed to join PCOC	Estimated number of PC services	
ACT & NSW	29	31 (88%)	35	
QLD	33	35 (80%)	44	
SA & NT	14	18 (75%)	24	
TAS	5	6 (86%)	7	
VIC	24	39 (85%)	46	
WA	12	15 (75%)	20	
Total	117	144 (81%)	176	

The PCOC, in collaboration with palliative care service providers, has agreed on four benchmarks to date for the assessment of palliative care service quality in Australia:

- Measure 1 Time from Referral to First Contact: This measure relates to the time taken for patients to be
 contacted and clinically assessed, once the palliative care team has received the patient's referral. To meet this
 benchmark, at least 90% of patients must be contacted within two days of receipt of referral.
- Measure 2 Time in Unstable Phase: The unstable phase type, by nature of its definition, alerts clinical staff
 to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Those
 patients assessed to be in the unstable phase require intense review for a short period of time. An unstable
 phase is triggered when a patient experiences a new unanticipated problem, experiences rapid increase in
 severity of existing problems or where the patient's family or carers experience a sudden change in
 circumstances that adversely impacts the patients care.
 - Unstable phases are ended when a new plan of care has been put in place, or when the patient is likely to die within days and is transitioned to the terminal care phase. To meet this benchmark, 85% (first care phase) and 90% (subsequent care phase) of patients must remain in an unstable condition for no longer than seven days, and the medium duration of unstable phase must be two days or less.
- Measure 3 Change in Pain: Pain management is acknowledged as a core business of palliative care
 services. The Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS)
 provide two different perspectives of pain: the SAS is patient rated, while the PCPSS is clinician rated. There
 are two benchmarks related to each tool: one relating to the management of pain for patients with absent or
 mild pain, and the other relating to the management of pain for patients with moderate or severe pain.
- Measure 4 Change in Symptoms Relative to the Baseline National Average: This measure includes a
 suite of case-mix adjusted scores used to compare the change in symptoms for similar patients i.e. patients in

the same phase who started with the same level of symptom. Change in these measures is compared against baseline data collected in 2008, and the benchmark is met where an improvement in scores has been achieved.

Using data from the PCOC, members of the collaborative have reported a 12-fold difference between specialist palliative care services on key patient and service level outcomes (such as pain and functional status), after controlling for factors including phase of illness and dependency. Moreover, around one third of those with cancer and 90% of those with non-malignant conditions in Australia never access specialist palliative care services. For these individuals, variations in health service outcomes are likely to be even more extreme. Palliative services for older people in Australia are also inadequate. The 2011 Productivity Commission Report into Caring for Older Australians noted that end of life care is poorly provided in residential aged care facilities, often resulting in preventable and costly transfers of residents to acute facilities. Internationally, a number of large studies have similarly reported gaps in end of life services, including: high rates of pain [13,14,15]; insufficient measures to limit aggressive care problems with respect to referral to palliative care services [16,17,18,19,20]; and professional resistance to share care with palliative care services.

PCOC data for Queensland in the period July to December 2011 is summarised in Table 2. Over this period, 3,044 patients were provided palliative care services in by PCOC participating organisations in Queensland including 2,350 via in-patient services and 991 via community and ambulatory services.

Table 2 PCOC Queensland Summary Measures for Benchmarks 1-3 22

Measure	Benchmark	Inpatient		Ambulatory & Community			
		QLD Score	Benchmark Met?	QLD Score	Benchmark Met?		
1. Time from referral to contact							
Benchmark 1: Patients contacted on same or following day	90%	94.8	Yes	60.3	No		
2. Time in unstable phase							
Benchmark 2.1: Unstable phases lasting for less than 7 days - first phase of episode	85%	84.0	No	67.9	No		
Benchmark 2.2: Unstable phases lasting for less than 7 days - not first phase of episode	90%	89.4	No	69.9	No		
Benchmark 2.3: Median time in unstable phase	2 days	2 days	Yes	3 days	No		
3. Change in pain PC Problem Severity Score							
Benchmark 3.1: Phases starting with absent/mild pain, that end with absent/mild pain	90%	86.4	No	74.7	No		
Benchmark 3.2: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	62.5	Yes	47.3	No		
Benchmark 3.3: Phases starting with absent/mild pain, that end with absent/mild pain	90%	87.6	No	74.3	No		
Benchmark 3.4: Phases starting with moderate/severe pain, that end with absent/mild pain	60%	51.7	No	43.5	No		

The PCOC data highlights substantial variation in the quality of palliative care services in Queensland, and emphasises the importance of systematic efforts to improve the effectiveness and efficiency of palliative care services.

Recommendations for Future Reform

A range of opportunities exist for reform to improve the quality and efficiency of palliative care services in Queensland.

- Improved Data and Reporting: To guide future planning of palliative care services, consistent definitions of data need to be developed and adopted by all palliative care services. This includes:
 - Consistent definitions for service features such as models of care, multidisciplinary and multi-professional team participation, bed types, and patient activity (e.g., occasions of service, telephone consultations, care types).

Strategies for improving coding, recording and collation of service data need to be identified to facilitate uniform data collection across all service providers involved in palliative care..

- Improved Access for Patients with Non-Malignant Conditions to Palliative Care: Cancer patients are far more likely to access palliative care services than those suffering from life limiting non-malignant conditions such as dementia, neuromuscular disorders (Multiple Sclerosis, Motor Neurone Disease, Parkinson's Disease) and heart failure. New strategies are required to increase the identification and referral of these patients to palliative and supportive care services and to increase the capacity of Queensland health service providers to address the diverse needs of patients with a range of non-malignant life limiting conditions.
- Improved Service Integration and Linkages: Integration of palliative care services within the health system, and linkages between palliative care services providers are key areas for further development if Queensland is to achieve its goals in relation to palliative care services. Effective linkages between service providers in rural and regional areas, and specialist providers in metropolitan areas are essential for the efficient functioning of a needs based service model in palliative care. Further research is necessary to examine the current and potential linkages between specialist and primary care services, and between specialist providers in metropolitan, regional and rural settings, to better understand how services can provide an integrated model of service delivery that is centred on population needs.
- Further research will also be required to better understand palliative care service provision in the primary care, community settings and residential care settings and how organisations can be supported to improve the quality of service. *Target Key Gaps in the Current Palliative Care System*: New strategies will be required to address key gaps in the current palliative care system in Queensland at a population level (targeting people of varying ages, people living alone without a caregiver, and people from indigenous and culturally and linguistically diverse backgrounds)²³ and at a service level (including respite services, after hours support, and bereavement services).
- Future Workforce Planning and Redesign: Workforce shortages represent a key challenge for the delivery of palliative care services in the future in Queensland. Slow rates of progress have been achieved in system wide reform areas such as competency based education, overlapping professional boundaries, new professional roles and extended scopes of practice. There is also concern about workloads for medical practitioners in palliative care, and the adequacy of training positions to meet future demands. Many nurses who work in palliative care work in mixed units and there is presently no agreed qualification framework for defining specialist palliative care nursing. Some smaller Health Service Districts do not have access to a Clinical Nurse Consultant in palliative care. The number of allied health professionals working in specialist palliative care services is limited, especially outside metropolitan areas. A more detailed and specialised analysis of workforce projections is required for future (succession) planning. Workforce shortages require that urgent attention be given to role redesign and innovation in care delivery.

Examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services

Integration of palliative care services within the health system, and linkages between palliative care services providers are key areas for further development if Queensland is to achieve its goals in relation to palliative care. Patient need must be placed at the centre of service planning initiatives and effective linkages between service providers are essential to ensure patients receive quality, timely and appropriate care, particularly in rural and regional areas of Queensland. To identify specific strategies needed to implement a needs based palliative care service delivery model in Queensland, further analysis is required to determine the extent to which the current distribution and features of specialist and primary care services meet current and projected population needs. This analysis should:

- give particular consideration to the needs of people with non-malignant as well as malignant conditions, people of varying ages, and people from indigenous and culturally and linguistically diverse backgrounds.
- examine in more depth the current and potential linkages between specialist and primary care services, and between specialist service providers in metropolitan, regional and rural settings, to better understand how services can provide an integrated model of service delivery.
- examine in more depth community palliative care service delivery.

About the IHBI Palliative Care Research Program

Launched in 2006, QUT's Institute of Health and Biomedical Innovation (IHBI) is devoted to improving the health of individuals and communities through research innovation, combining high quality health research with a commitment to social justice. IHBI occupies a unique position in the Australian health and medical research establishment, with a commitment to cross-disciplinary research and community engagement, and a particular focus on applied projects with the potential to have an impact in the medium term. Over the past decade, QUT and IHBI have played a key leadership role in research, training, clinical engagement and contribution to policy in the field of palliative and supportive care in Australia. The IHBI Palliative Care Research Group was established in 2005 and has grown to comprise over 30 researchers and research staff across a range of clinical and other disciplines. This group is now established as a recognised leader in the Queensland and Australian palliative care community, undertaking a range of projects targeted at improving the quality and accessibility of palliative care services. Key projects led by the group include:

Quality and Capacity Improvement Projects

- Program of Experience in the Palliative Approach (PEPA): A clinical placement program, funded by the Australian Government, for generalist health professionals and human service providers across Australia which aims to improve skills and expertise in palliative care. PEPA is offered in all Australian States and Territories across urban and rural contexts. PEPA is available for GPs, nurses, allied health practitioners, Aboriginal and Torres Strait Islander health professionals, aged care staff and other health practitioners.
- Palliative Care Curriculum for Undergraduates (PCC4U): PCC4U develops, promotes and provides
 resources for the incorporation of palliative care education within undergraduate medical, nursing and allied
 health courses. The PCC4U initiative has engaged with 125 education programs at 38 Australian Universities
 representing 59% of all relevant health professional undergraduate programs. This program is funded by the
 Australian Government.
- Palliative Care Outcomes Collaboration (PCOC): PCOC is a national program funded by the Australian Government that uses standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. PCOC holds clinical outcome data on more than 80% of all patients seen by specialist palliative care services across Australia.

Primary Research Program

Symptom Control:

- Randomised Controlled Trial in Nausea Management: A two-stage trial of antiemetic therapy in patients with cancer and nausea not related to anticancer therapy. NHMRC Funded.
- Randomised Controlled Trial of Non-Pharmacological Interventions for Dyspnoea: The primary aim of
 this study is to evaluate the efficacy of a brief tailored intervention incorporating breathing exercises and
 targeted psychological support to reduce dyspnoea and improve function in people with cancer.

Health Services

- Tracking Pathways for Advanced Cancer Patient: A prospective, longitudinal study of pathways for advanced cancer patients focusing on quantifying the health & support needs of patients with advanced cancer and their carers, and mapping service utilisation over time. This project is funded by the Cancer Council Queensland.
- Our Journey Through Dementia: A project focusing on the development of a palliative approach to the care of patients with dementia funded under the DoHA Local Palliative Care Grants Scheme.

Further details of ongoing QUT research activities in the area of palliative care are provided as an attachment.

Summary

In summary, we believe the delivery of effective, efficient, adequate and equitable palliative care services in Queensland in the future will be dependent on action in the following key areas:

- More consistent and coordinated collection of data on palliative and supportive care services in Queensland to enable enhanced planning for future service needs.
- Better integration and linkages between the community care sector and specialist providers at all levels to
 ensure that patients are referred to services on the basis on need.
- Targeting of key gaps in the palliative care system both in terms of population groups (including patients with non-malignant conditions, older patients, indigenous patients and patients from CALD backgrounds) and in terms of specific service areas (including respite services, after hours support, and bereavement services)
- Improved engagement with the community care and non-Government sector to develop, trial and implement
 patient centred models of care and to shift the burden of care from the acute setting to sub-acute and
 community based services.
- Improved training and development programs which enhance and maintain the palliative care skills of the generalist and specialist health workforce in Queensland in preparation for future workforce shortages.
- Greater investment in research to inform improved service planning and policy, and to drive the adoption of evidence based interventions and models of care to raise the standard of palliative care in Queensland.

I would like to thank the Committee for the opportunity to contribute to Queensland Government policy in the provision of palliative, frail and chronic care services. I would be happy to discuss any of these issues in further detail with you or the committee members as required.

Yours Sincerely

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Appendix 1 - Palliative Care Australia Resource and Capability Framework26

Level	Capability	Typical Resource Profile
Primary care	Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care. Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care level 1	Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. Has quality and audit program.	Multi – disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.
Specialist palliative care level 2	As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the Community. Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.	Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.
Specialist palliative care level 3	Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has comprehensive research and teaching role. Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.	Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.

Appendix 2 – QUT Palliative Care Research Program: Key Programs and Research Projects

Tracking pathways of patients with advanced cancer

Quantifying the health and support needs of patients with advanced cancer and their primary informal carers over the six-month period prior to death and to map patients' movements within and between health services during this time.

Funded by Cancer Council Queensland.



Palliative care outcomes improved through collaboration

PCOC is a national collaboration, funded by the Department of Health & Ageing (DoHA) under the National Palliative Care Program. Collaborating partners are University of Wollongong (Lead), Flinders University, QUT and University of Western Australia.

www.pcoc.org.au



National implementation of sustainable cancer nursing education initiatives to support the cancer control workforce.

Funded through Australian Government Cancer Australia.

www.cancerlearning.gov.au

A two-stage trial of antiemetic therapy in patients with cancer and nausea not related to anticancer therapy.

Funded by the National Health and Medical Research Council (NHMRC).

Sponsored by the Palliative Care Clinical Studies Collaborative (PaCCSC).



The Development of Cancer Survivor Self-management Plans project will enable further understanding of ways to promote sustained self-management abilities in patients following completion of active cancer treatment, thereby improving the health outcomes for the growing population of cancer survivors.

Funded through DoHA's Sharing Health Care Initiative.

Supportive and palliative care research at QUT

Workforce development in palliative care



Funded by the Australian Government Department of Health and Ageing

PEPA offers primary health care professionals subsidised short-term workforce placements with specialist palliative care services and a tailored workshop program.

www.pepaeducation.com



An interactive web-based training module to develop the skills of health professionals providing psychosexual care to women and their partners affected by gynaecological cancers.

A National Centre for Gynaecological Cancers initiative funded by the Australian Government.

www.cancerlearning.gov.au

OUR JOURNEY through DEMENTIA

A palliative approach to dementia

This Department of Health and Ageing Project, funded under the Local Palliative Care Grants Scheme, aims to improve the quality of care for people with dementia, and their carers in a range of residential aged-care facilities, involving three aged care providers in Qld and NSW.

Embedding palliative care content in undergraduate curricula



Funded by the Australian Government Department of Health and Ageing

Supporting the inclusion of palliative care in all health care education and training.

www.pcc4u.org



www.ihbi.qut.edu.au





References

² Phillips JL. & Currow DC. (2010) Cancer as a chronic disease. *Collegian*. **17**: 47-50.

Australian Government Productivity Commission. (2005) Costs of death and health expenditure Technical Paper Economic Implications of an Ageing Australia, Productivity Commission Research Report.

World Health Organisation, WHO Definition of Palliative Care, http://www.who.int/cancer/palliative/definition/en/, Accessed 16-07-12

Hardy, J R, Haberecht, J, Maresco-Pennisi, Diane, & Yates, Patsy (2007) Audit of the Care of the Dying in a Network of Hospitals and Institutions in Queensland. Internal Medicine Journal, 37(5), pp. 315-319.

⁷ Yates, Patsy, Edwards, Helen E., Nash, Robyn E., Walsh, Anne M., Fentiman, Belinda J., Skerman, Helen M., McDowell, Jan K., & Najman, Jackob M. (2002) Barriers to Effective Cancer Pain Management: A Survey of Hospitalized Cancer Patients in Australia. Journal of Pain and Symptom Management, 23(5), pp. 393-405.

Living Longer. Living Better. Aged Care Reform Package April 2012, Australian Government, http://www.health.gov.au/internet/main/publishing.nsf/Content/D47F3C99304A50E5CA2579E50080D9C0/\$File/AG ED%20CARE%20REFORM%20PACKAGE.pdf Accessed 02 August 2012

⁹ Palliative Care Services, Clinical Services Capability Framework version 3.0, Queensland Health, http://www.health.gld.gov.au/cscf/docs/24 palliative.pdf Accessed 3-8-12

Currow DC et al. (2008) Is it feasible and desirable to collect voluntarily quality and outcome data nationally in palliative oncology care? J Clin Oncol. 26(23): 3853-3859.

Rosenwax LK & McNamara BA. (2006) Who receives specialist palliative care in Western Australia – and who misses out? Palliat Med. 20: 439-445.

¹² Productivity Commission 2011, Caring for Older Australians, Report No. 53, Final Inquiry Report, Canberra.

¹³ The SUPPORT Principal Investigators. (1995) A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA. **247**(20): 1591-1598.

14 Desbiens NA et al. (1996) Pain and satisfaction with pain control in seriously ill hospitalized adults: findings from

the SUPPORT research investigations. Crit Care Med. 24(12): 1953-1961.

¹⁵ Somogyi-Zalud E et al. (2000) Elderly persons' last six months of life: findings from the Hospitalized Elderly Longitudinal Project. J Am Geriatr Soc. 48(5 Suppl): S131-S139.

¹⁶ Higginson I et al. (1994) Reducing hospital beds for patients with advanced cancer. *Lancet.* **344**(8919): 409.

¹⁷ Burge F et al. (2002) Population-based trends in referral of the elderly to a comprehensive palliative care programme. *Palliat Med.* **16**: 255-256.

Heedman PA & Starkhammar H. (2002) Patterns of referral to a palliative care unit: an indicator of different attitudes toward the dying patient? J Palliat Med. 5: 101-106.

Ahmed N et al. (2004) Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med.* **18**: 525-542.

National Audit Office. (2008) End of Life Care. HC 1043 Session 2007-2008. The Stationary Office: London.

²¹ Miller KE et al.(1997) Barriers to hospice care: family physicians' perceptions. *Hospice J.* **12**: 29-41.

²² Outcomes in Palliative Care Report 12, July – December 2011, 2012, Palliative Care Outcomes Collaborative ²³ Aoun, Samar, Kristjanson, Linda, Currow, David, Skett, K, Oldham, L, & Yates, Patsy (2007) Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs. Palliative Medicine, 21, pp. 29-34.

²⁴ Turner, J., Clavarino, Alexandra, Yates, Patsy, Hargraves, Maryanne, Connors, Veronica B., & Hausmann, Sue (2007) Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs. Psycho-Oncology: journal of the psychological, social and behavioral dimensions of cancer, 16(2), pp. 149-157.

²⁵ Yates, Patsy, Evans, A, Moore, A, Heartfield, M, Gibson, T, & Luxford, Karen (2007) Competency Standards and Educational Requirements for Specialist Breast Nurses in Australia. Collegian, 14(1), p. 11.

²⁶ Australian Bureau of Statistics (ABS). *Population by Age and Sex, Australian States and Territories* 3201.0 Australian Demographic Statistics, Jun 2011. 2011 [cited 2012 July 17]; Available from: http://www.abs.gov.au/ausstats/abs@.nsf/0/AE3CAF747F4751CDCA2579CF000F9ABC?OpenDocument

¹ Australian Government Department of Health and Ageing. (2010) Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy. Barton, Commonwealth Department of Health and Ageing.

³ Palliative Care Australia (PCA). (2005) A Guide to Palliative Care Service Development: A Population Based Approach. Palliative Care Australia: Deakin West.