

Dear Colleagues

Welcome to the Second Annual Research Conference for the Centre for Palliative Research and Education. The CPCRE Annual Research conference aims to provide the palliative community in Queensland with an opportunity to discuss some of latest research in the field of palliative care. The research that is being presented at this year's conference covers a broad spectrum of issues in palliative care education, practice and policy. We hope you find the conference to be interesting, challenging and enjoyable.

Warm regards

Patsy Yates
Director of Research
Centre for Palliative Care Research and Education

The Centre for Palliative Care Research and Education

The Centre for Palliative Care Research and Education (CPCRE) is a Queensland Health initiative whose primary role is to enhance palliative care services in Queensland, through research and education endeavours.

To achieve these aims, the CPCRE operates as a 'centre without walls', committed to building and fostering partnerships with the palliative care community in its endeavours.

Our Key Functions

The key functions of CPCRE are to:

- To promote improved accessibility to palliative care education for all disciplines
- To facilitate high quality, evidence based educational initiatives in palliative care
- To foster a culture of lifelong learning amongst disciplines within the palliative care community
- To promote the utilisation of research in palliative care policy and practice
- To develop the capacity of the palliative care community to undertake research
- To undertake research that leads to advances in palliative care services
- To contribute to the development of palliative care policy through consultation and collaboration with government and non-government bodies

CONFERENCE PROGRAM

0830 – 0900 Registration

0900 – 0915 Welcome and Opening Address

0915 – 1000 Keynote Address: Professor Linda Kristjanson
**‘Building Partnerships in Palliative Care Research:
Ideas, People & Visions’**

1000 – 1030 Morning Tea

1030 – 1215 Morning Presentations

Time	Speakers	Topic
1030 – 1050	Dr Judy Wollin (<i>Lecturer QUT</i>)	Palliative care needs of people with neurodegenerative disorders
1050 – 1110	Professor Jenny Abbey (<i>QUT/ The Prince Charles Hospital</i>)	Pain: The experience of people with dementia
1110 – 1130	Ms Deborah Prior (<i>Ph.D Candidate, UQ</i>)	Aboriginal women dying to be at home - Findings of an ethnographic study
1130 – 1150	Ms Samantha Fitzgerald & Ms Michelle Crawford (<i>Project Team, Toowoomba Division of General Practice</i>)	SEAM: Support Education Assessment and Monitoring Service for regional and rural people
1150 – 1215	Dr Louise Welch (<i>VMO Consultant, Cairns Base Hospital, Medical Superintendent Gordonvale Memorial Hospital Palliative Care & Respite Unit</i>)	Developing an on-line educational resource for General Practitioners in rural and remote areas for the Australian College of Rural and Remote Medicine (ACRRM)

1215 – 1300 Lunch

1300 – 1430 Afternoon Presentations

Session One – Clinical and Psychospiritual Issues

Time	Speakers	Topic
1300 – 1315	Dr Paul Glare (<i>RPAH</i>)	Does the palliative prognostic (PAP) score work for oncologists?
1315 – 1330	Dr Alison Howat (<i>The Prince Charles Hospital</i>)	To investigate whether hyaluronidase can improve subcutaneous absorption of fluid in palliative care patients
1330 – 1345	Cecelia Boyd (<i>QUT</i>)	Waiting for a transplant: Patient experiences
1345 – 1400	Dr Paul Glare (<i>RPAH</i>)	Improving the management of nausea in advanced cancer: Pragmatic tools for the assessment and treatment of nausea in clinical practice
1400 – 1415	Monika Wilson (<i>QUT/Karuna</i>)	Re-storying the dying self: A narrative investigation of self-identity complexities at the end of life

Session Two – Educational and Paediatric Issues

Time	Speakers	Topic
1300 – 1315	Fiona Israel (<i>Mt Olivet</i>)	Research study into the educational, training and support needs of general practitioners in palliative care: Reflections on interviews conducted with carers
1315 – 1330	John Rosenberg & Debbie Canning (<i>CPCRE</i>)	A foot in the door of isolated practice: Reaping the benefits of an evaluation process
1330 – 1345	Dr Liz Reymond (<i>Mt Olivet</i>)	A pilot study for the delivery of an interactive strategy aimed at increasing the palliative care capacity of primary health care providers working in rural and remote areas of Australia
1345 – 1400	Dr Helen Irving (<i>Banksia Unit, Royal Children's Hospital</i>)	Challenges, successes and innovations in delivery of palliative care to children and adolescents dying from cancer
1400 – 1415	Dr Peter Whan & Dr Lynn Wales (<i>UQ</i>)	Sinecure or curate's egg? – Uncovering the meaning and use of palliative care
1430 – 1530	Panel Discussion:	“Turning Research Into Practice”
	Facilitator: Dr Will Cairns (<i>Medical Director, Townsville & District Palliative Care Service</i>)	
	Panel:	
	Ms Linda Barrett (<i>Palliative Care Coordinator, Bayside Health Service District</i>)	
	Dr Geoff Mitchell (<i>Centre for General Practice, UQ</i>)	
	The Reverend Ann Dittmar-McCollim (<i>Coordinating Chaplain, St Luke's Nursing Service</i>)	
	Ms Jo Root (<i>Manager, Aged & Community Care Reform Unit, Queensland Health</i>)	
1530 – 1545	Professor Linda Kristjanson	Conference Summation
1545		Conference Close

**Keynote Address: Building Partnerships in Palliative Care
Research: Ideas, People & Visions**

Professor Linda Kristjanson: *Cancer Foundation of WA Chair of Palliative Care, School of Nursing & Public Health, Edith Cowan University, Pearson Street, Churchlands, WA 6018.*

This paper will focus on the importance of partnerships and collaboration in developing palliative care knowledge. The current state of palliative care research will be reviewed with an analysis of areas of strength, barriers to research progress and promising directions. The essential elements to developing partnerships in palliative care research will be outlined with examples from current multi-site studies and international collaborative projects. Mechanisms and strategies for enhancing partnerships will also be examined with a focus on how Australian palliative care researchers and clinicians can work together to advance our evidence for practice.

Palliative care needs of people with neurodegenerative disorders

Dr Judy Wollin, *Lecturer, School of Nursing, QUT.*

Professor Linda Kristjanson, *Edith Cowan University, Western Australia.*

Associate Professor Kathryn White, *Edith Cowan University, Western Australia.*

A qualitative study was undertaken to assess the supportive care needs of people with multiple sclerosis (MS), motor neurone disease (MND), Parkinson's Disease (PD) and Huntington's Disease (HD) and their families. The specific aims of this qualitative study were to:

- Assess the effectiveness of existing supportive care services to people with MND, MS, PD, or HD, and their families.
- Identify the unique needs of people with these diseases and their carers.
- Identify issues for carers that are inadequately addressed.

In-depth interviews (135) were undertaken across Australia. Important conclusions were drawn from the interviews, and will be used as the basis for the survey in Phase 2 of the study.

- Individuals and carers preferred the option of home care.
 - Carers needed support services to provide care and they needed to maintain their own health to continue in the caring role.
 - Home care was perceived to be the most cost effective service.
 - Care in the home required many services and health professionals.
 - Support services required funding to include children as recipients of care.
 - Hospitalisation and residential care did not often meet needs.
 - The future was difficult to consider, or to plan for.
 - Financial resources were limited in many families due to loss of income, and the cost of care in the home.
 - Funding of services was restricted and not consistent across communities and facilities.
 - The associations were excellent sources of support, knowledge, information and equipment. However, meeting other people with the same conditions could be confronting.
 - Health care workers in this field needed specialized training and skills.
 - Palliative care had a role in some care services, particularly the care of those living with motor neurone disease and included counselling, future planning, end of life issues, symptom control and crisis management.
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Pain: The experience of people with dementia

Professor Jenny Abbey, *School of Nursing, Queensland University of Technology, The Prince Charles Hospital Health Service District.*

The implementation of well-organised palliative care for people with dementia is little understood and only recently recognised as needing a specific specialised clinical regime. The recognition and treatment of pain is an important factor in this management and yet it has consistently been found that pain is under-diagnosed and under-treated in this population. This paper briefly describes the development of a pain scale for residents in aged care facilities, who were in the end-stages of a dementing illness and had become unable to verbalise their needs. Results showed there was a significant change in the pain scale score pre and post intervention. However, there were limitations in data collection and analysis. In spite of these, the scale has been circulated to facilities in Australia and been received as a useful clinical device.

This paper will present

- Background to the development of the scale. The need for a clinical instrument that would supply, in an efficient and effective way, a record of staff observations which they consider represent pain in residents with end-stage dementia.
 - Development of the scale. Some reflections on research within aged care facilities
 - Main research findings. Score on pain scale was reduced following interventions.
 - Limitations of research. Staff's judgement the 'gold standard'. Difficulty with measuring inter-rater reliability
 - Presentation of scale
 - Report of initial responses from distribution to 3000 accredited residential facilities of scale, educational poster and letter to DONs
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Aboriginal women dying to be at home – findings of an Ethnographic Study

Deborah Prior, *University of Queensland/Consultant in Palliative Care Research and Education.*

The aim of my research was to explore Aboriginal women's perspective and experience of cancer and its associated treatment and care options. Previous studies revealed that Aboriginal women experienced high morbidity and mortality from cancer because of advanced disease at presentation. Yet paradoxically they shied away from accessing both curative and palliative care services. Among the complexity of findings from my research was the overwhelming need of Aboriginal women to be in their communities and with their family when facing life-threatening illness. Many of the women who participated in my research either chose to abandon their course of prescribed cancer treatment or not to pursue any conventional treatment options for fear of leaving their community. Other reasons for this were also complex and included Aboriginal women's fear of the cancer care environment and hospitals generally; cultural care needs; feeling of isolation and loneliness; communication difficulties, perceived racism; and spiritual distress associated with being separated from their homeland. In this paper I will provide an overview of my methodology and detail the major findings of the ethnographic study in two rural Aboriginal communities.

SEAM: Support education assessment and monitoring service for regional and rural people

Samantha Fitzgerald: *Project Team, GP Connections, Toowoomba and District Division of General Practice*

Michelle Crawford: *GP Connections, Toowoomba and District Division of General Practice*

SEAM is a new model of service delivery for palliative care patients that will be fully sustainable by the end of the second year of the project. The service, to be provided by GP Connections in partnership with the Toowoomba Hospice, will be based at the Toowoomba Hospice. SEAM involves the employment of a Registered Nurse for 30 hours per week to take on the role of Case Manager in the area of Palliative Care.

Developing an on-line educational resource for General Practitioners in rural and remote areas for the Australian College of Rural and Remote Medicine (ACRRM)

Dr Louise Welch: *VMO Consultant, Cairns Base Hospital; Medical Superintendent, Gordonvale Memorial Hospital Palliative Care and Respite Unit.*

Many initiatives involving education for General Practitioners have appeared following studies, literature reviews and expert committee consultations showed the need for palliative care education from undergraduate and registrar levels to practicing GPs. This project followed a submission guided by the above and specifically relates to the needs of Rural and Remote General Practitioners and their preferred or accessible method of learning. These GPs have very limited access to educational activities due to geographic isolation. Studies have indicated that general practitioners prefer the didactic lecture format. In Rural and Remote communities this is often impossible to provide. Either the GPs are unable to leave their community or the teacher is unable to attend locally. Out of pocket costs and lack of backfill are some of the major hurdles. Another preferred method was problem-based learning activities. Distance learning courses were seen as easier to attend.

The ACRRM (Australian College of Rural and Remote Medicine) On-line Palliative Care Modules for General Practitioners are based on a case study format with levels or layers of interest. The aim is not to provide an on-line textbook of palliative medicine but to stimulate interest and provide a basic level of competency. Exercises and tasks often require self-reflection and examination of current practices. "Click here" opportunities provide direct information or links about further resources and contacts.

The focus is to enable the GP's to apply the case studies to their own environment and encourage case management processes specific to their situation. Emphasis is placed on increasing community support for the client, carers and families by empowering the GP.

In general, information is based on guidelines from current literature, textbooks and journals. Networking with regional specialised palliative care service providers is encouraged. Information is provided that can be downloaded for personal reference or as patient handouts.

Following publication on the website, evaluation of the Project will take place on the RRMEO site.

Does the palliative prognostic (PAP) score work for oncologists?

Dr Paul Glare, *Royal Prince Alfred Hospital, Camperdown, NSW.*

Patrick McMahon, *Royal Prince Alfred Hospital, Camperdown, NSW.*

Dr Steffen Eychmueller, *Royal Prince Alfred Hospital, Camperdown, NSW.*

Aim: To test the predictive power of the PaP score – which combines symptoms, performance status (PS), and lymphocyte counts with the physician's survival estimate (PSE) to reliably predict the short term survival of patients with advanced cancer referred to palliative care services - in the hands of Medical and Radiation Oncologists.

Method: When applied to 100 consecutive hospitalised patients with advanced cancer prior to palliative care referral. The PSE was provided by the Oncologist in charge of the patient's care

Findings: 52 patients were still receiving systemic anti-cancer treatment. 62 reported anorexia, 36 dyspnoea. Karnofsky PS score was >50 in 64. The PSE was > 3 months in 55, < 1 month in 10. Severe lymphopenia ($<12\%$ total white cell count) occurred in 73. The actual median survival was 83.5 days; the PaP score distinguished three distinct groups A, B, and C (log rank 57.06, $P<0.0001$) with median survival 102 (A, $n=65$), 22 (B, $n=33$) and 2 (C, $n=3$) days respectively. Although PaP performed well for oncologists, the small number of patients in Group C limits its usefulness. It seems to be a specific prognostic tool for palliative care populations.

To investigate whether hyaluronidase can improve subcutaneous absorption of fluid in palliative care patients

Dr Alison Howat: *Advanced Trainee Palliative Medicine, The Prince Charles Hospital*

Dr Carol Douglas: *Deputy Director, The Palliative Care Unit, The Prince Charles Hospital*

Dr Grant Cameron: *The Palliative Care Unit, The Prince Charles Hospital*

Toni Bradley: *Clinical Nurse Manager, The Palliative Care Unit, The Prince Charles Hospital*

Dr Harry Barlett: *School of Mathematical Science, Queensland University of Technology*

Aim: To perform a prospective observational study assessing the efficacy of hyaluronidase in improving absorption of subcutaneous fluids in palliative care patients requiring supplementary hydration.

Method: Observational Study to be conducted in two parts. Informed consent will be obtained from the patients or their next of kin/health advocate. The first part involves all subjects recruited and subcutaneous fluids will be administered according to best practice guidelines. In addition to current practice observations of the site a Visual Analogue Scale recording into the site status will be recorded for each nursing shift by nurses of the palliative care unit. The total volume of fluid administered in a 24 hour period will also be recorded along with any adverse consequences of the infusion. Other demographic and fictional data including diagnosis, body mass index, Waterlow score Karnosky Performance Scale, (Palliative Performance Scale) and time to death will be recorded.

Patients with impaired absorption as observed with swelling, pain or pooling of the fluid subcutaneously requiring two episodes of repositioning of the subcutaneous site within a forty-eight hour period will proceed to the second part of the study. This involves the addition of 750 units of hyaluronidase to the subcutaneous fluid. The hyaluronidase will be dissolved in 1 ml of sterile normal saline and injected into the tubing of the subcutaneous fluid administration apparatus. This procedure will be repeated after 24 hours as the enzyme loses activity beyond 24 hours. The subcutaneous sites will be observed and data recorded as for the first part of the study.

Waiting for a transplant: Patient experiences

Cecelia Boyd: *PhD Student, Queensland University of Technology.*

Transplantation is a recognised treatment protocol for the person suffering with end stage disease of the heart, lung, kidney, liver or marrow. Currently, 1806 people are listed as organ transplant candidates in Australia. Not all of these people will receive a transplant as the person may become critically ill and die before an organ may be found. Of the 1750 people on the waiting lists for organ transplants in Australia in 2002, only 694 (40%) received a transplant. There were 206 donors of organs to meet these transplant needs. These figures reflect international recipient donor ratios where there are 8.5 potential solid organ recipients to each donor (8.5:1). The remaining 60% of potential recipients either continued waiting, became critically ill and were removed from the waiting list, or died. The purpose of this study is to examine the adequacy of current models of care for the person waiting for a transplant. More specifically the objectives are (1) to describe the physical, emotional, spiritual and psychosocial needs for people during the time of waiting for a transplant; (2) to identify the predictors for quality of life and symptom distress using the domains of patient demographics, psychosocial and spiritual variables, and transplant type; and (3) to explore the experiences of people waiting for a transplant within the health care service system. This prospective study measures the selected domains and variables between three timepoints over a twelve month period using validated quantitative instruments.

**Improving the management of nausea in advanced cancer:
Pragmatic tools for the assessment and treatment of nausea in
clinical practice.**

Dr Paul Glare, *Royal Prince Alfred Hospital, Camperdown, NSW.*

Dr Martin Stockler, *Department Medical Oncology, Royal Prince Alfred Hospital, Camperdown, NSW.*

Professor Martin Tattersall, *Department Cancer Medicine, Royal Prince Alfred Hospital, Camperdown.*

Professor Linda Kristjanson, *Edith Cowan University*

Aim: This NHMRC funded project aims to develop pragmatic tools for non-specialists to improve the assessment and treatment of nausea in clinical practice.

Method: An evidence-based clinical practice guideline (CPG) for the management of nausea in advanced cancer will be developed which form the basis of the pragmatic tools. The tools will then be tested in clinical practice. A systematic review (SR) of the literature will form the basis of the CPG.

Findings: the SR is currently in preparation. It is due for completion prior to the first 6-monthly report to the NHMRC on the project's progress (due date 30/6/03). The results of the SR will be presented.

Re-Storying the Dying Self: A narrative investigation of self-identity complexities at the end of life.

Monika Wilson, *Queensland University of Technology, with the assistance of Karuna Hospice Service.*

My research utilised a narrative methodology to focus on the question of how a person's sense of self or self-identity is affected throughout the living-dying process. This presentation outlines the findings of this research, which include the various shapes and forms of the 'assaults' on self-identity at this time. The narratives collected eloquently inform us of the things that are important to living-dying people's sense of self and, generally, their experiences of the living-dying process. These findings then translate into new caring possibilities to provide opportunities for living-dying people to construct and reconstruct their self-identity – to re-story the dying self. The ways that living-dying people, palliative care practitioners, family and friends can assist in this 're-storying' are the main focus of this presentation.

The presentation also briefly covers the role of ethics as it relates to this process – the aim being to transform palliative care ethics into one that is inclusive of a collaborative ethic of care, and an openness to, and the ability to listen with, the voice of the living-dying person. I call this an ethic of listening.

Research study into the educational, training and support needs of general practitioners in palliative care: Reflections on interviews conducted with carers

Fiona Israel, *Palliative Care Research Unit, Mt Olivet Community Services.*

Dr Liz Reymond, *Palliative Care Research Unit, Mt Olivet Hospital.*

Dr Geoff Mitchell, *University of Queensland.*

Associate Professor Barry McGrath, *University of Melbourne.*

Doug Welch, *Redcliffe-Bribie-Caboolture Division of General Practice.*

Aim: To assess the perceptions of recently bereaved carers regarding the quality of palliative care provided in the community setting by the patient's GP.

Method: Carer perceptions of the palliative care received by their loved-ones is important in determining the quality of community based palliative care provided by GPs. In this study carers were invited to talk about their experiences of that care. Half the carers were self-selected in that they responded to an advertisement in a local newspaper and half the carers were approached through the deceased patient's GP. Carers were recruited across three target populations - indigenous and transcultural communities, rural and remote communities and patients in home-based and residential aged care facilities. Carers were interviewed face-to-face, at a venue of their choice, using a semi-structured framework. The framework was based upon the five quality domains, physical, psychological, social, spiritual and cultural, that underpin specialist palliative care practice. Interviews were taped and transcribed verbatim. Transcripts were then analysed thematically.

Findings: Carers are often unable to fully define their palliative care needs because the palliative experience is intensely unfamiliar, unstable and emotionally distressing. Nonetheless carers can easily articulate emotional responses to that experience. There were many common issues raised across the target populations. For instance, carers volunteered statements about the importance of relationships with GPs that extended beyond the patient's disease, the GPs availability, the necessity for well co-ordinated community services and the availability of bereavement care. These themes will be discussed as well as population specific findings.

A pilot study for the delivery of an interactive strategy aimed at increasing the palliative care capacity of primary health-care providers working in rural and remote areas of Australia.

Dr Liz Reymond, *Medical Officer, Palliative Services & Director, Palliative Care Research Unit, Mt Olivet Hospital.*

Denyse Haseman, *Mt Olivet Hospital, Palliative Services.*

Fiona Israel, *Mt Olivet Hospital, Palliative Services.*

Aim: To pilot and evaluate an interactive support strategy aimed at increasing the palliative care capacity of primary health-care providers working in rural and remote areas of Australia.

Method: The project is based on workshops delivered at four different rural and remote sites in far north Queensland. The workshops will involve as many members of the local primary health-care team as practicable. Relevant team members are expected to include people such as GPs, nurses, allied health professionals, Aboriginal health workers, volunteers, counsellors, pastoral care workers and other therapists working across community, hospital and residential aged-care environments. Some workshop sessions will include all participants while others will be profession or topic specific. Initially, potential participants will be asked to complete and return a self-administered questionnaire. Responses will be used to tailor workshop content, based on local clinical cases and issues, for each particular site. In addition the research officer, with input from other local health care professionals, will use questionnaire data to produce a local palliative service directory and resource document for distribution. The workshop intervention will be primarily evaluated using repeated measures questionnaires that are profession specific. Differences in responses to pre and post-workshop questionnaires will be analysed quantitatively and qualitatively.

Findings: To date, four sites have been chosen to run workshops: Thursday Island, Cooktown, Atherton, and Mareeba. The first workshop – on Thursday Island – has already been held; the remaining three will be held in June.

Many thanks to the Queensland Cancer Fund for supporting this study.

Challenges, successes and innovations in delivery of palliative care to children and adolescents dying from cancer

Dr Helen Irving, *Banksia Unit, Royal Children's Hospital.*

Lee-Anne Pedersen, *Banksia Unit, Royal Children's Hospital.*

Delma Pfingst, *Banksia Unit, Royal Children's Hospital.*

Michelle Noyes, *Banksia Unit, Royal Children's Hospital.*

Objectives: To review and enhance the provision of palliative care to children dying from malignancy across a vast geographical area.

Methods: The Royal Children's Hospital, Brisbane is the major tertiary referral centre for children with malignancy throughout Queensland, northern NSW, parts of the Northern Territory, with occasional referrals from the Pacific Rim. The needs of health professionals in these areas, and families caring for a child dying from cancer have previously been ascertained. "A practical guide to paediatric oncology palliative care" for health professionals was developed as a component of the prior study. Service provision has expanded to incorporate a 24-hour on call service, and been reviewed. Additional innovative ways of delivery of patient care, such as telemedicine have also been investigated.

Results: The majority of patients requiring palliative care live outside the immediate metropolitan area, and receive coordinated, multidisciplinary, multi-site care. Review of the health professional's guide has indicated widespread utilisation. As a result of the needs of families, "Palliative care for children with cancer – A guide for parents" has recently been published. The 24-hour on call service provides home visits for families and telephone contact across the State for families and health professionals. Telemedicine can also be incorporated into these services, enabling direct visual links with the Royal Children's Hospital team, local health care providers, and the child and family, thereby facilitating communication and care. This method of health care will have particular benefit for families in rural and some remote locations.

Conclusions: Geographical isolation and sparse population away from the major paediatric centre, create challenges to families and health care professionals caring for children, from both metropolitan and rural perspective. The Royal Children's Hospital has been instrumental in the development of strategies, such as written guides, education programs, a statewide on call service, and utilisation of more innovative means of health care delivery, to optimise delivery of palliative care to children and their families in the place of choice.

Sinecure or curate's egg? – Uncovering the meaning and use of palliative care

Dr Peter Whan, *Centre for Online Health, University of Queensland.*

Dr Lynn Wales, *Senior Lecturer – School of English, University of Queensland.*

Aim: To provide a framework for appropriate critical examination of Palliative Care, by exploring the history of its core terminology.

Method: Electronic and print resources were searched for words and phrases related to 'palliative', 'care' and 'cure'. The etymology of these terms, noting some cross-linguistic differences, was related to some controversies arising in contemporary Palliative Care practice.

Results: 'Cure' used to mean 'care' or 'concern', and the earliest-appearing term most similar to today's usage is not 'palliative care' but 'palliative cure'. 'Cure' (meaning to eliminate disease) as the expected outcome of health work is a modern concept. The collocation 'Palliative Care' was apparently independently coined by two North American surgeons in the 1960's-70's. 'Sinecure' means "a job without responsibilities". A 'curate's egg' (Punch, 1895) means something which is "good in parts".

Conclusion: The divergent meanings of 'cure' and 'care' have produced controversy. Critics of Palliative Care may dismiss the discipline as a "bad egg", denigrating it as a sinecure on the grounds that its practitioners are relieved of the responsibility to cure. This study has shown, however, that the modern meaning of *cure* is a recent narrowing of the broader sense of *care*. Palliative Care embraces the enduring responsibility to care which remains when cure is not an option. On the other hand, if practitioners respond to criticism of Palliative Care simply by claiming (in the spirit of the Punch cartoon) that "parts of it are excellent", they merely palliate deficiencies which need to be faced honestly.

Keynote Speaker: Dr Linda Kristjanson is the Professor of Palliative Care Nursing at Edith Cowan University and Director of Hospice Research for Silver Chain Hospice Service in Western Australia. She also serves as Research Consultant to the Cancer Clinical Services Unit at Sir Charles Gairdner Hospital in Perth, Western Australia. Dr Kristjanson leads a number of palliative care research teams, focusing on the care needs of terminally ill patients and their families.

Dr Judy Wollin has been a lecturer at QUT for twelve years with a particular interest in disability. She has completed research addressing information needs of people with multiple sclerosis (MS), carer burden, the impact of incontinence on the lives of people with MS. Dr Wollin has also completed research working with MSQ, MS Support Groups and the Blue Care Specialist Clinic, Mt Gravatt. Judy is secretary of MS Nurses Australia Inc. a support and education group for nurses working with people with MS.

Dr Jenny Abbey has been a hands-on-nurse practitioner, a union organiser, Assistant Dean, Research, at Flinders University and a health-care consultant. The needs of people with dementia have been an interest of hers for at least two decades. Her initial PhD research, and subsequent work which brought her into contact with many nurses, has shown that conflict about pain management, especially for people with dementia who cannot articulate their needs, is very common. She is concerned about the effect this conflict on the person with dementia, who may remain in pain, the strain on professional relationships and the added difficulties and distress this places on a family. She hopes that her pain scale will contribute to some relief of this situation.

Deborah Prior has an extensive professional history as a nurse educator and most recently principle lecturer in palliative care at ACU from 1992. Deborah played a key role in the development of palliative care education and policy through her position as chair of Palliative Care Queensland and executive member of Palliative Care Australia. Her present services to palliative care include Vice Chairperson of the Board of Karuna Hospice Service, Member of the Expert Evaluation Advisory Group for the Commonwealth Department of Health and Ageing CCP program. Also Deborah is currently enjoying life as a full time PhD. student with UQ, where she is completing her thesis on Aboriginal women's experience and perceptions of cancer and its related treatment –care options.

Samantha Fitzgerald is a Program Officer with GP Connections. Sam's background includes professional acting, teaching and public relations. Currently she is completing her Masters in Education with a focus on online and distributed learning. Sam is coordinating the SEAM project.

Michelle Crawford graduated with a Bachelor of Nursing with Distinction in 1992. She has worked in a number of areas in hospital settings and in a busy general practice. Michelle commenced the SEAM Nurse position in April 2003.

Dr Louise Welch graduated from the University of Queensland in 1977. She worked at Cairns Base Hospital for four years, and then had one year as locum medical registrar in the UK. She has been in general practice in Cairns since 1982, with six

months time out in Fellowship training at Palliative Care, Mt Olivet Hospice, Brisbane in 1992. She completed a Graduate Diploma in Family Medicine at Monash University in 1996, and a Masters Palliative Medicine at Flinders University in 2000. In 2001 she was admitted to the Fellowship Royal Australian College of General Practitioners, and in 2002 to the Fellowship Australian Chapter of Palliative Medicine. She is currently working part time as a general practitioner, and also as a consultant in palliative medicine at Cairns Base Hospital and Gordonvale Memorial Hospital Palliative Care Unit. She is also involved in the ongoing education of medical and nursing staff, community groups, volunteers, and health workers.

Dr Paul Glare is senior staff specialist physician in Palliative Medicine at RPAH and Area Head, Palliative Care Services in CSAHS. He is also Clinical Senior Lecturer, Dept of Medicine, University of Sydney. As well as having more than 10 years clinical experience in palliative care, he is actively involved in teaching and research in that speciality. One of his principal research interests is prognostication. This year he has been awarded a NHMRC Palliative Care Strategic Research Development grant to develop a pragmatic tool to aid the management of nausea in advanced cancer. He has also been awarded a Caring Communities Project grant to study the predictors of home death in patients with advanced cancer. He is currently completing a Masters of Medicine in Clinical Epidemiology through the School of Public Health and for the treatise he is undertaking a survival analysis of palliative care referrals for the treatise.

Dr Alison Howat is currently working as an Advanced Trainee in Palliative Medicine at The Prince Charles Hospital. She qualified from the University of Glasgow in 1995 and underwent general medical training in Scotland. She was successful in gaining MRCP (UK) in 1998. She travelled to Queensland in 1999 and worked for a year in Bundaberg Base Hospital. During this time she met her future husband and decided to settle in Australia. She moved to Brisbane and joined the physician training scheme. She was successful in the FRACP examination in 2002. During her training she thoroughly enjoyed working with palliative care patients and found the field very satisfying and so has commenced Advanced Training in the speciality.

Cecelia Boyd: As a clinical academic Cecelia has worked predominantly in Oncology/Haematology nursing since 1987. She has worked clinically in this field in Brisbane at the Royal Brisbane Hospital, Royal Children's Hospital and the Mater Health Services, and in London, UK at the Hammersmith Hospital. Her clinical experience spans the oncology / haematology and bone marrow transplant inpatient and day care outpatient services, apheresis and palliative care. She has worked in the role of project officer for the Queensland Nursing Council and the University of Queensland and as a research assistant at a number of institutions. Among her achievements are two interactive educational CD Roms for medical student education. The first is on breast cancer (CAMEO-B) and the second on pap smears and cervical cancer. Between 1998 and 2002 she held the position of joint lecturer between the Mater Health Services and the Australian Catholic University in Oncology and Palliative Care and was a member of the Palliative Care Flagship. Since then, she has been the recipient of an NHMRC student scholarship for this research and she has been employed at the Mater Education Centre as an Educator in oncology and Palliative Care part time whilst studying full time at QUT. Professionally she has been the National Editor of the Transplant Nurses Journal, National President of the

Transplant Nurses Association, Executive for the Oncology Nurses Group at the Queensland Cancer Fund and been on several committees for the Cancer Nurses Society of Australia, and other steering committees relating to cancer education. Her research area focuses on patient experiences whilst waiting for a transplant.

Monika Wilson currently carries out the roles of postgraduate student/researcher, student learning advisor, and tutor/lecturer in Applied Ethics and Human Services at the Queensland University of Technology, Carseldine campus. She completed an undergraduate degree in Social Sciences (Human Services-Aged Care and Applied Ethics), a Bachelor of Arts (Honours) in Applied Ethics and is currently finalising a Master of Counselling. Monika has a keen interest in improving end-of-life-care and focuses her research on self-identity challenges and complexities and reconceptualising applied ethics in palliative care. She complements her academic work with volunteer work at the Karuna Hospice Service, Mount Olivett and SIDS & Kids on their 24-hour child death support line.

Fiona Israel has in one way or another been involved in palliative care nursing since the late 1980's, initially in both inpatient and community settings in South Australia, and more recently in Brisbane where she has worked with the Karuna Hospice Service and Mt Olivett Hospice. She is currently involved in research and is based at the Palliative Care Research Unit at Mt Olivett Hospice Services. She is in the final year of a masters programme at QUT.

John Rosenberg is a Research Officer with the Centre for Palliative Care Research and Education (CPCRE). John's nursing career began twenty years ago at Wangaratta Hospital in north-east Victoria. Since that time, he has worked in a variety of clinical settings – inpatient oncology, inpatient hospice, and community palliative care – and as an educator and researcher in the care of people at the end of life. He is a frequent public speaker at seminars and conferences.

John returned to study in 1991 and has gained a Bachelor of Nursing from la Trobe University in Melbourne, a Graduate Diploma in Nursing (Palliative Care) from the Australian Catholic University in Brisbane, and the degree of Master of Palliative Care from the Flinders' University of South Australia.

John participates in many groups related to end of life care. In the past, he has been an executive member of Palliative Care Queensland and a member of a number of its committees. He is a member of the Oncology Nurses' Group – Brisbane, and a past Chair of the Palliative Care Network – Brisbane Forum.

In November 2002, John moved from service delivery to his current research officer position, ahead of his planned commencement of doctoral studies in 2004. In addition to supporting educational research projects, John is responsible for the Library Information Service, and the CPCRE Book Review program.

Debbie Canning is currently the Director of Education at the Centre for Palliative Care Research and Education (CPCRE), and until recently, held a Visiting Academic position at QUT's School of Nursing where she taught in both undergraduate and postgraduate courses. Prior to joining the CPCRE, Debbie worked at St Luke's Nursing Service – a community nursing organisation, as the Palliative Care Clinical

Educator, where a major part of her role involved coordinating the “Palliative Care: a community nursing approach” (on campus/distance) course.

Debbie’s formative years were spent specialising in Oncology/Haematology, before journeying towards palliative care via Mt Olivet Hospice, Prince Charles Hospital and the community. A visit to Calcutta in 1988, where she worked at several of Mother Theresa’s facilities as well as a street clinic run by Irish medico, Dr Jack Prager, made a significant impact on this journey, both professionally and personally.

Prior to St Luke’s, Debbie was appointed as Queensland’s first Clinical Nurse Consultant, Palliative Care at the Princess Alexandra Hospital, co-ordinating the PAH/Mt Olivet Palliative Care Hospitals Consultative Service from 1992-1998. During this time she visited many districts throughout Queensland, giving seminars and education updates.

Debbie is a member of several Palliative Care/Oncology and Education professional bodies and holds postgraduate qualifications in Palliative Care and a Masters degree in Nursing Leadership. She is contemplating doctoral studies in the area of palliative care education.

Dr Liz Reymond: Prior to becoming a GP, Liz had an academic career based at the Research School of Biological Sciences at the Australian National University. Currently employed at Mount Olivet Hospice Services as a Medical Officer and Director of the Palliative Care Research Unit her research interests revolve around symptom management in palliative care patients. In her position as Consultant Medical Educator for General Practice Education Australia she delivers lectures in palliative symptom control and organises palliative case discussions for GP Training Registrars.

Dr Helen Irving: not available at time of printing

Dr Peter Whan undertook his medical training at the University of Queensland, and graduated in 1976. Following hospital residencies in Brisbane in 1977, he gained a broad range of experience at the Redcliffe Hospital, from 1978 to 1985. He then worked as a missionary in Kenya for two years, returning to Australia and medicine in 1987. He took up a position as Senior Medical Officer at the Redcliffe Hospital in November 1990.

He worked in the Palliative Care Service there until October 1999, when he left to take up PhD research at the University of Queensland. He has been Visiting Medical Officer in Palliative Care, Bundaberg Health Service District since April 2000.

He is a State Council member of Palliative Care Queensland, a Council delegate of Palliative Care Australia, a member of the Australian and New Zealand Society for Palliative Medicine and a Fellow of the Australasian Chapter of Palliative Medicine.

He hopes that his research into the Knowledge and Knowledge-system of Palliative Care will ultimately assist workers of all kinds to create, disseminate, access, appraise and use knowledge for the care of dying people and those close to them.

Dr Lynn Wales graduated from the University of London in 1961 with an honours degree in Latin with Greek, also qualifying as a secondary teacher at the Institute of Education.

Following three years of research on Roman history at the University of London and six years of secondary teaching in Scotland, she began an academic career in linguistics, receiving a research Masters (on Latin syntax) from the University of Edinburgh and a PhD (on future reference in French) from Monash University.

Since arriving in Australia in 1976 she has researched and taught linguistics at Monash University, the University of Melbourne and the University of Queensland. She is also an applied linguist, her research areas being linguistics in education, literacy education and second language education. She has researched and taught applied linguistics at Deakin University and at the University of Queensland.

Her current research interests include the documenting of the National Literacy Strategy in the UK; developing a cross-linguistic grammar of English for Mandarin speakers; the analysis of tense and modal usage in French newspapers.

She has two sons, from whom she has also learned a lot about language!