

President's Report

When you help, you see life as weak. When you fix, you see life as broken. When you serve, you see life as whole. Fixing and helping may be the work of the ego, and service the work of the soul.

- Rachel Naomi Remen

I was struck by this quote when reading a book by Christina Puchalski - "A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying". It challenged me to think about when do I really serve, and when do I seek to fix, or help. More importantly it reminded me to be aware of leaving my ego 'at the door' when seeing patients and trying hard to connect with each patient. This, of course, is much harder than it sounds, and there are some people we naturally connect with, and others with whom we never seem to connect. It illustrates the importance of teams and teamwork in working in Palliative Care.

Taking over the presidency of ANZSPM I was struck by the willingness of people to get involved and serve, simply for a greater good. As part of beginning a new presidency, I find myself remembering a lot of people who have brought the organisation to where it is, and from whom the current ANZSPM council has been given 'stewardship' to move the organisation into the future. In particular I would like to pay tribute to Odette Spruyt, ANZSPM's past president and current councillor. Odette was only on the council a short time and bravely (or perhaps naively) took on the presidency. The thing I have learnt most from Odette is to always focus on a larger vision. Her vision has enabled our organisation to be a forward looking, focussed organisation that is no longer just reacting to what occurs, but planning directions for the future.

The ANZSPM conference in Darwin was very well attended, with 213 registrants, and I would like to thank Mark Boughey (convenor) and Will Organise (conference organisers). It was fantastic to catch up with colleagues from Australia, New Zealand and other overseas countries. The heat and humidity were amazing as was some of the natural beauty the Northern Territory has on show. The invited speakers were well received, as were the posters, proffered papers and workshops. Sharing knowledge is important as always, but so too are the social events, and these were very much enjoyed by all.

I would like to pay tribute to three departing councillors from the ANZSPM Council. Janet Hardy has been a wonderful newsletter editor (another thanks to Odette for taking this on), and valued member of council. Greg Crawford and Pat Treston have been on the council for as long as I can remember. Greg was newsletter editor for many years, and like Janet, contributed a lot to keep this tool of communication going. He has been a source of calm wisdom over the years, and we are very pleased to have him as the convenor for the next ANZSPM conference in Adelaide 2010. Pat has

ANZSPM, PO BOX 238, Braidwood, NSW, 2622

Ph: 0458 203 229, Fax: 03 8677 7619

Email: karen@anzspm.org.au

Dr Phillip Good	President	Email:
		president@anzspm.org.au
Prof Janet Hardy	Newsletter Editor	Email:
		editor@anzspm.org.au
Karen Cooper	Executive Director	Email:
		karen@anzspm.org.au
Website		www.anzspm.org.au

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ANZSPM membership renewal

ANZSPM membership renewals are now due. If you have not received your renewal notice or have misplaced it, please email Karen at karen@anzspm.org.au

been treasurer for many years, and has successfully handed the reins over to Mary McNulty. We are all thankful for Pat's ability to maintain the financial position of the organisation, as well as do the many statutory tasks associated with auditing, financial statements etc. that don't always come naturally to doctors.

I also would like to thank all the ANZSPM members who represent ANZSPM on various committees. Their contribution is highly valued by the Council, and enables a strong voice for Palliative Medicine in Australia and New Zealand.

In terms of looking to the future there are many important issues for ANZSPM. The priorities I see for this council are to:

1. Continue to look at our working relationship with the Chapter of Palliative Medicine to see where we can both be more efficient and prominent in Palliative Care matters.
2. Working with Palliative Care Australia to ensure palliative medicine practitioners continue to have a voice in the larger Palliative Care environment

3. Remuneration issues via item numbers.
4. Workforce planning, both via attracting increased numbers of trainees, and trying to develop guidelines on minimum staffing for provision of Palliative Medicine services.
5. Constitutional reform to make the functions of the society more streamlined
6. Continue the development of clinical indicators
7. Continuing professional development for all doctors with an interest in Palliative Care.

In regards to continuing professional development, we are very pleased to announce a series of education forums to be held in the first half of next year. Thanks to a generous sponsorship from MundiPharma, these are planned to be held in capital cities of Australia and three venues in New Zealand. ANZSPM will be organising these evening forums, aimed at palliative care specialists, trainees, other specialists with an interest in palliative care and also general practitioners. The format will be a talk by an invited speaker followed by a discussion session based around case presentations by local specialists/general practitioners. Keep a lookout for the dates in your local area.

Phillip Good, Newcastle

New Zealand Branch Report

These newsletters come around very quickly so thank goodness, there are always new things happening in Palliative Care in New Zealand. The main items of news are as follows.

Palliative Care Council (PCC) of New Zealand.

After several years of hard work, there has been at last a development in the formation of a national body representing Palliative Care needs. Unfortunately this has not developed into the umbrella body originally envisaged by the advisory group - PCAC which was comprised of representatives of all the palliative care stakeholders. However it is hopefully a step in the right direction. This new group is called the Palliative Care Council of New Zealand.

The role of the Council will be to provide strategic advice to the Minister of Health via the Cancer Control Council on issues relevant to palliative care. The Council is made up of 8 members from the "specialist" Palliative Care sector and in addition has consumer and Maori representation. The Council will also establish advisory groups as required to ensure that wider expertise is available to maximise all advice given to the Minister.

The 8 representatives include those nominated by the New Zealand Branch of ANZSPM, Hospice New Zealand, Hospital Palliative Care New Zealand and Palliative Care Nurses New Zealand. The first chair of the Council will be selected from these four nominations.

The ANZSPM NZ Branch representative is Carol McAllum. Carol is a vocationally trained Palliative Medicine Specialist with a background in general practice. She has a range of experience across a number of sectors including general practice, hospice (in-patient and community) and hospital settings. As such we believe she will bring a helpful depth and breadth of insight to the Council.

Senior clinical advisor for Palliative Care to the Ministry of Health

This is a new part-time position recently established by the Ministry of Health in New Zealand. Simon Allan, who is well known to Palliative Care in New Zealand and Australia has been appointed to this position and will hopefully give an update on the development of this role in future newsletters. Both Carol and Simon have been long time ANZSPM members and supporters of the Society and have been on the NZ Executive in the past in office bearing roles. We are happy that Carol has now joined our Executive again and will be able to provide feedback to ANZSPM on the activities of the new Council.

Hospice New Zealand Conference

This recent conference held in Palmerston North at the end of October was extremely successful with great feedback from many disciplines. They were fortunate in having a number of excellent keynote speakers including our own hard working ANZSPM newsletter editor - Janet Hardy. The academic content of the conference was not the only highlight. The conference dinner was the social event of the year with a "flower power" theme which saw a number of well known palliative care health professionals (some not recognisable!!!) dancing the night away to a 60's -70's band par excellence.

Wishing you the best for Christmas and the New Year

Joy Percy (NZ Branch Chair)

Trainee Report

Of course the main news this newsletter is the conference in Darwin which many trainees attended. For the trainees the conference started early with the trainee day on the Tuesday, with presentations from the plenary speakers. Dr Declan Walsh, Dr Tony Egan and Dr Michael Wright were kind enough to give their time to pass on their wisdom to the trainees regarding the business of palliative care, being educators and on the state of palliative medicine around the world.

This started a busy week for many of us with the next 3 days solid with presentations and workshops. It was great to see the number of registrars who had abstracts accepted to present research either in a poster or as a verbal presentation. Having the opportunity to present your work at conference is not only good experience but the feed back from colleagues can be used for future development of your work, and may introduce new ideas or new directions you may want to take. I encourage all trainees to submit abstracts for either PCA conference (Perth) in 2009 or the next ANZSPM conference (Adelaide) in 2010.

I don't want to go through the rest of the conference itinerary in detail as I'm sure everyone has taken away what they wanted from the sessions they attended. Once again I found myself trying to split myself in two wanting to be in different sessions at the same time.

In 2009, ANZSPM would like to encourage increased trainee contribution to the newsletter. If you have read any journal articles or books that you think will be of particular interest to trainees please email a review to the editor of the newsletter. Also in 2009 there is going to be another trainee day, this time in Canberra. Once again it will be held about April/May and we will do our best to avoid any clashes with other meetings etc. Many thanks to Michael Chapman, dual trainee in Palliative Medicine and Geriatrics, for being the man on the ground to organise venues and speakers. I will email out details of the training day once dates have been finalised.

I hope you all have a happy and safe holiday season and best wishes for the New Year and I look forward to seeing many of you in Canberra.

**Scott King,
Melbourne**

Advertisement

The Tasmanian Association for Hospice and Palliative Care & the Tasmanian Palliative Care Service

Palliative Medicine 'Retreat' for specialists in Palliative Medicine.

As in previous years, the program content and format will evolve throughout the two-day meeting, and will be guided by the wishes and interests of participants.

Principal theme for 2009: Philosophy and Palliative Medicine

Convenor: Dr Paul Dunne

Co-facilitators: Professor Michael Ashby, Assoc Professor Brian Stoffell

Program: the program is iterative and interactive, and will develop from the issues participants bring to the retreat. You are invited to bring along your own cases for discussion and you may also wish to bring along a reflection (prose, poetry, music or images) which you find meaningful and would wish to share with the group.

Salamanca Inn, 10 Gladstone Street, Hobart

5-6 March 2009

For registration form, email: paul.dunne@dhhs.tas.gov.au

ANZSPM Conference Highlights

"Inspirations and Innovations" was the theme of the 8th biennial ANZSPM conference in Darwin in late September, and inspiration and sharing of new insights was certainly achieved by the organisers. We all were brought to awareness of the Larrakeyah Nation, with the welcome speech and impressively vibrant display of dance at the commencement of proceedings.

Through the program we were offered a sharing of stories... listening, learning, teaching, resting..... In addition to discussion of symptom and patient care issues, two prominent connections brought a focus to Palliative Care involving aboriginal Australians and the challenges of our self care.

Declan Walsh gave overview insights to the rationale of Palliative Care services, and also challenged us to see the increasing role of palliative medicine within a modern oncology setting. The need for symptom management to move beyond pain and GI concerns to the distressing problems of fatigue, anorexia and cachexia was stressed. Judicious use of methylphenidate and dexamethasone may well provide some improvement for affected patients. The global perspective of palliation raised in Michael Wright's address challenged each of us to deep consideration of cultural and spiritual aspects. Michael's beautiful photo illustrations were a true delight!

Helen Austin gave a special presentation bringing a collective sigh of agreement with her poignant telling of one family's journey through the all-too-familiar maze of the ill-effects of steroid use and associated issues.

Mark Boughey opened the plenary session with a moving consideration of cultural aspects of care – where to be, with whom to share. This led seamlessly on to

Hugh Heggie's tale of "Bruce" bringing the challenges of providing care in the vastness of Northern Australia into focus. He and other presenters taught much of the importance of flexibility and improvisation in providing care for terminal illness.

I was privileged to be among the group to visit Darwin Hospice, the highlight of which was hearing of the construction of The Labyrinth and briefly being immersed in its significance.

Socially the ANZSPM program was highly memorable. Drinks and cocktails out on the lawn at Parliament House was such a serene way to welcome. Mindil markets greeted us with an amazing array of international foods, and provided many of the delegates with precious items as gifts and souvenirs. Many of us visited the NT museum and gained a new admiration for the spirit of Australians especially those of the North, learning of the tragedy of war years and of Cyclone Tracey's devastation. Of course, sunset over Cornucopia lawns was then a striking backdrop to our conference dinner, with a final chance to foster relationships within the ANZSPM network.

Darwin itself did not disappoint- the sunshine enabled enjoyment of the sights, with swimming in the evening a special treat to winter-affected southerners. The deck chair cinema gave a novel evening out.

Following the conference, I was fortunate to experience the Top End at leisure, and to gaze in awe at ancient rock paintings at Nourlangie Rock, and over the plainlands of Kakadu, followed by vistas from the small (scary) scenic flight scooping over the Escarpment! Magnetic Termite Mounds fascinated, whilst floating under the pure water of Florence Falls cascading into a tranquil pool was an invigorating unforgettable experience. Wildlife on Yellow Water did not disappoint as we spotted crocodiles and species upon species of bird in their calm rich habitat. I personally came away refreshed and enthused, grateful to my northern colleagues for putting together such a tableau.

Judith McEniery, Brisbane

Darwin Highlights

Going to Darwin at this balmy time of year triggered my memories of Africa – in particular Harare with its low lying buildings, flowering trees lining the city streets, brown dusty earth and laid back outdoors lifestyle. It made me nostalgic and led me to think Darwin might be a nice place to live for a period. As with many conferences the highlights included the networking and social functions that Darwinians (Darwintonians?) are blessed to be able to hold outdoors.

The conference opening included story telling and dance by members of the local aboriginal peoples, the Larrakeyah, on whose land the conference was being held. I found it very moving to hear the story of the land and the impact that losing access to it had had on the indigenous owners. It was reminiscent of other places where I have lived, including South Africa and New Zealand.

The welcome reception was held on the impressive "Speaker's Green" of Parliament House, overlooking Darwin Harbour, to the sounds of a string trio at sunset. Imagine a warm summery night, a stately building, green lawns, a glass of wine, a glowing orange sun sinking slowly at first, then more rapidly and suddenly it's dark...



Another social activity was a trip to Mindil Beach Markets, again at sunset, with the unexpected surprise of vouchers to spend at the markets. I spent mine on the beautiful tropical fruit (pawpaws and mangoes) that vendors had cut up for sale. There is nothing more indulgent than having someone else cut your fruit up for you! Lots to look at, buy, eat and drink - a delightful evening, in very pleasant company.

Last but not least there was the conference dinner, held once again outdoors on the Cornucopia lawns, at sunset (yet another glorious one). These lawns are adjacent to the Northern Territory Museum, which has a wonderful collection of aboriginal artworks that we were able to visit courtesy of the conference – a "must see" in my opinion.

Well, what about the presentations? There was plenty to choose from, and they covered the full gamut of palliative care including:

- **symptom management** (the comprehensive update on opioid induced hyperalgesia delivered by Penny Briscoe, an informative talk on the use of intranasal sufentanil for episodic pain by Phillip Good and the fascinating presentation by Lara Hoskins on the management of painful priapism)
- **advance care planning** (an interesting presentation on the ability to prognosticate in patients with heart failure by Juli Moran, and helpful perspectives about the improvement that can be achieved by careful choice of wording when discussing advance care planning prepared by Eric Fairbanks but kindly delivered by one of his colleagues on his behalf)
- **psychosocial issues** (managing challenging patients and assessing depression in geriatric palliative patients by Greg Crawford)
- **quality initiatives** (the interesting finding emerging from the work of the Palliative Care Outcomes Collaboration, presented by David Currow and the inspirational presentations by Melanie Benson who reported on her research experiences as the Victorian Quality Council Fellow)

Last but by no means least, there were the invited speakers. Declan Walsh, Michael Wright and Tony Egan.

Declan Walsh, Professor and Director at The Harry R Horvitz Center for Palliative Medicine in the USA spoke about the challenges involved in managing cancer related fatigue, the cachexia anorexia syndrome and the research program he has been involved in around these topics.

He also spoke about the interface between palliative care and oncology in the USA, how the relationship has changed and how it might change in the future.

Particularly useful to me was the idea he presented of the significant skill set we bring to the clinical interface, which we could perhaps consider promoting a little more. The skill set he proposed includes communication skills, decision making skills, managing complications, symptom control, psychosocial care, care of the dying and care co-ordination. To our amusement he shared with us the illuminating term "Premature Palliation", used by one of his oncology colleagues. This certainly struck a cord with me as I thought back to how many times I have heard the words "But (s)he is not ready for palliative care yet!" Michael Wright, Research Fellow from Lancaster University in the UK drew on the oral history archive of the International Observatory on End of Life Care program to give a thoughtful presentation about what might motivate palliative care practitioners to enter this career. This archive includes a collection of around 700 interviews with hospice and palliative care activists from 52 countries, and provides a rich and interesting resource. It was fascinating to hear about an early interview with Eduard Bruera. What a visionary idea to begin this archive in the early days of palliative care.

Tony Egan, teaching Fellow from Dunedin School of Medicine in New Zealand gave an interesting presentation on role modelling in teaching, pointing out that trainees watch and learn from everything, including from undesirable behaviour or comments. I left this talk reminded that any member of the "community of clinical practice" in which the student finds themselves becomes a role model, even if unintended. Trainees and students learn from everything they see, hear or experience, and modelling appropriate behaviours is critical to optimum learning outcomes.

This speaker also heightened my awareness that students "have a legitimate presence; they have a right to contribute and a need to feel that they are accepted by that group".

Finally I was also reminded that we only learn by making mistakes and need to promote an environment that encourages learning from reflection, for example by using tools such as the suggested "Thought Provoking Episode Report".

Overall I found the conference stimulating. I came away with several pages of ideas to follow-up, lots of references to explore and some useful suggestions to put into practice. It was well worth the 10 hours travel time to get there.

Cathy Miller, Auckland

Profile - Dr Josephine Clayton

(This is a new segment in the ANZSPM newsletter where we aim to celebrate the achievements of our members).



Josephine has been recently awarded the University of Sydney Cancer Research Network Innovation Award for her oral presentation at the Sydney Cancer Conference 2008. This award is given to an early career researcher (less than 10 years postdoctoral) presenting the most exciting new idea on an important issue in cancer research and/or treatment.

Her presentation was on the 'Clinical practice Guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life-limiting illness'. This is Josephine's fifth research award.

Currently Staff Specialist in Palliative Medicine and Head of the Palliative Care Department at Royal North Shore Hospital, she also has an appointment as a Senior Lecturer and Cancer Institute NSW Clinical Research Fellow in the Faculty of Medicine and the Centre for Medical Psychology and Evidence Based Decision Making (CeMPED) at the University of Sydney.

Her major research interest is communication about prognosis, end-of-life issues and palliative care and she has published several articles in peer reviewed journals on this topic. She is currently the principle investigator of a project evaluating an evidence based training program to teach skills around end of life discussions to resident medical officers. She is a chief investigator on a NHMRC project grant for 2009 which will involve undertaking a randomised controlled trial of a doctor/nurse/patient intervention aiming to improve quality of life at the end of life. Her other interest is in obtaining evidence for medications used in palliative care. She is the Lead site investigator for Royal North Shore Hospital Palliative Care Department's successful bid as a Phase 4 site (pharmacovigilance studies) in Flinders University's National Palliative Care Clinical Studies Collaborative (PaCCSC).

Josephine is involved in many committees developing and planning for palliative care services and reviewing end-of-life decision making in the Northern Sydney Central Coast Area Health Service. She is co-chair of the Australasian Chapter of Palliative Medicine - Communication Module Working Party. This has involved developing a communication skills training module for advanced trainees in Palliative Medicine. The module

will also be available for Continuing Professional Development (CPD) for Specialists in Palliative Medicine. The module will be launched in December 2008, together with a training program for future facilitators of the course being conducted by three visiting international experts.

Karen Cooper
Executive Director, ANZSPM

NHMRC Grants

The third round of the Program provides \$4.205 million over 4 years from 2006 to 2010 to fund research and activities that will develop capacity within the palliative care research community. The Program comprises the following components: Research development grants, Priority driven research grants and Training awards, (comprising PhD Scholarships and Postdoctoral Fellowships). The purpose of the Palliative Care Research Development Grants is to provide opportunities for emerging investigators and research teams to build capacity and foster the potential to develop significant careers in palliative care research. They are also intended to provide a building block on which future projects can be developed and submitted to the NHMRC (or other organisation) for funding. In August 2008 the Minister for Health and Ageing, the Hon Nicola Roxon MP, approved 16 grants totalling nearly \$740,000. Several ANZSPM members have been successful in obtaining these grants. Summaries of some of the projects are listed below. For full details, please consult the NHMRC website www.nhmrc.com.au.

1. Informing the development of a model of care for patients with end stage COPD: what are their care needs and are they being met?

Currently there is no specific model of care for people with end stage chronic obstructive pulmonary disease (COPD), despite growing evidence of the specific symptoms and issues of this patient group. Interviews with end stage COPD patients and their carers will be undertaken to explore the services currently being accessed, and how well patients' needs are being met by these services. This project will conduct an audit of available services in South Australia and then examine how hospital, specialist palliative care units and primary care services (including general practice) can interface to meet these identified patient and carer needs.

The results from this study will be used to inform development of a distinct model (or models) of care that addresses the needs of patients with end stage COPD.

Chief Investigators: Greg Crawford, Mary Brooksbank, Margaret Brown, Alan Crockett, Teresa Burgess

2 Prospective study of Medical Emergency Team (MET) calls to define issues of end of life decision making, symptoms and transition in goals of care.

Patients having MET calls are often seriously ill with life limiting illnesses. This study aims to explore various aspects of communication, particularly focusing on changing goals of care; and also the symptoms that may be causing significant distress for the patient, to assist development of interventions that will aim to improve quality of life and also communication in the setting of medical emergencies in patients with life limiting illness. This research will be conducted as a collaboration between the Simpson Centre of Health Services research, University of New South Wales (Prof Ken Hillman, and Dr Jack Chen) and Sydney South West Area Palliative Care Service (Dr Meera Agar, Dr Louise Elliott, Ms Janeane Harlum, Ms Colleen Carter, Dr Jennifer Wiltshire).

3. Randomised control trial of risperidone versus haloperidol versus placebo with rescue in delirium in palliative care.

This study is comparing the three approaches for the management of delirium symptoms: efficacy of oral risperidone solution, oral haloperidol solution and control (oral placebo solution with subcutaneous midazolam rescue), in control of targeted delirium symptoms at 72 hours from treatment commencement, in addition to nonpharmacological strategies and assessment for reversible precipitants. This grant in particular is for a substudy to explore the pathophysiological correlates - serum markers of neuronal apoptosis (S 100 beta, neuron specific enolase and other serum markers) over time which have been associated with delirium and may predict poor outcomes. The chief investigators for this project are Dr Meera Agar, A/Prof Gideon Caplan, A/Prof Brian Draper, Ms Debra Rowett, Dr Chris Sanderson, A/Prof Peter Lawlor, Dr Simon Eckermann, Prof David Currow, Dr Mark Hill, Dr John Plummer and Ms Tania Shelby-James.

4. An evaluation of the validity of measuring salivary oxycodone concentrations for pharmacokinetic studies in palliative care patients

The primary aim of this study is to assess the validity

of using salivary concentrations of oxycodone and/or its metabolites as a non-invasive valid alternative to plasma sampling. The study we also explore the patient experience and preferences for saliva sampling versus venipuncture. The ultimate aim is to determine population pharmacokinetics of oxycodone and its metabolites in palliative care patients of all ages, especially in those with organ dysfunction.

Chief investigators : J Hardy, R Norris, B Charles

5. Comparing the effectiveness of paracetamol and placebos in advanced cancer patients on opioids.

The role of paracetamol in the management of pain in patients with advanced cancer on opioids needs to be defined. N-of-1 trials are randomized, double-blind cross-over comparisons of active drug with placebo or another drug. The patient is their own control. N-of-1 trials provide objective means of testing effectiveness of medicines in individuals, providing evidence stronger than randomised controlled trial evidence for the efficacy of that drug in that individual. We will pilot n-of-1 trials of paracetamol for pain in 10 patients. If feasible, this will be a new method of obtaining strong evidence in a difficult to research population: palliative care patients.

Chief investigators : J Nickles, G Mitchell, J Hardy, D Currow, R Vora, P Schuler, M Yelland, C del Mar

Pioneers and Gurus

Few other countries pay homage to elders as well as does India. The respect paid to leaders is enormous and the depth of feeling expressed in simple gestures such as bending to touch the feet of a guru or saint is very touching to behold. Such was the expression of gratitude paid by Dr Sukdev Nayak, the president of the IAPC toward Dr Robert Twycross at the inaugural ceremony of the XV IAPC conference in Kochi, Kerala in February this year. The depth of feeling in Dr Rajgopal's introduction of Dr Twycross was also inspiring. These men have long been colleagues dedicated to establishing and nurturing palliative care development in India over the past 15 years and their shared struggles and commitment was evident in this moment of the inaugural ceremony.

The conference theme was Quality and Coverage. There has been work on developing standards for Indian Palliative care since 2006, leading to the preparation and presentation of a draft document "National Standards in Palliative Care". The discussion around this document during a conference plenary session has stayed with me for its resonance with similar issues faced by us in

Australia as we extend the boundaries of palliative care to non-malignant illness, needs based (rather than prognosis based) care which results in earlier and intermittent involvement and also to other settings of care such as residential aged care facilities. Already some say that palliative care has lost its holistic aspect, perhaps in part because of the current highly valued ethic of equity of access to specialist care when needed and the resultant stretching of our resources to achieve this. Thus there has been a stripping down to bare minimum of service provision, care "brokerage" and the loss of something that made palliative care different in the first place. In India, the discussion was more around minimum standards that should be met to ensure safe practice. For example, a standard was proposed that states that doctors and nurses working in a palliative care service have at least 10 days of training in palliative care. The proposed standards can be found on www.palliumindia.org if you are interested to find out more about them.

The conference had quite a large international faculty, many of whom are regular visitors to India, such as Dr Jeremy Johnson, his wife Penny and team members, Gary Kirlew and Bill Gretch, all from Severn Hospice, Shrewsbury. This hospice has been twinned with Karunashraya Hospice in Bangalore for many years and led to multiple exchanges between the two services.



There were a number of Australian and New Zealand participants as well as others from USA, South Africa, UK, Uganda and Malaysia. The general style of the conference was welcoming and relaxed with many young volunteers adding an element of excitement and enthusiasm. I was struck by the ongoing presence of a core of highly committed doctors and nurses who have been responding to the enormous challenges of establishing palliative care since the first conference in 1994. While there has been considerable development, there are also many disappointments to be borne along the way. Successes include the multidisciplinary membership of IAPC of over

400, the regular newsletter and annual conference, the advocacy and success in improving opioid availability in several states, and the ongoing attraction of young, enthusiastic doctors and nurses to this field. However, there is so far little extension beyond the disciplines of medicine and nursing, overall opioid prescription and consumption is very low (less than 1mg per capita per year) and the need for palliative care continues to outpace the rate of development of this field. The continued lack of integration into the medical system of care in India means that the majority of patients fail to receive palliative care of even the most basic type. Many doctors continue to work in this field in a voluntary capacity or are paid minimal wages and health administrators view it as an optional extra, if at all. Some of the pioneers betray a sense of urgency and distress about the slowness of progress and the unrelieved burden of patient suffering still so prevalent. I could only marvel at the dedication and determination of these same pioneers in their continued efforts despite the enormous odds.

India has a special magic, a special music. We were treated to a wonderful selection of performances of music, dance and martial arts in the Bhoghatty Palace during the conference banquet. Being transported by boat to participate in the conference and watching the sunset over Kochi Harbour, with its fishing boats and bustling life, was especially beautiful.

After the conference, I participated in a refresher course organised by Pallium India in Thiruvananthapuram (Trivandrum), in southern Kerala, which ran from 15-17 Feb. I was one of 18 faculty members and 29 participants. Dr Mhoira Leng, (who worked as a registrar in Sydney in the late 1990s), was course chairman and with colleagues, Raelee Jensen (NZ palliative care nurse) and Dr Baburaj Chakrapani, organised a very interactive and creative program. The emphasis on group work, plenty of interaction between course participants and faculty, role plays with volunteer actors, and minimal didactic teaching provided a good teaching model to follow in the future. A particular strength was the focus on case based teaching. The cases were real life and evoked much discussion around the best form of palliation in the circumstances described rather than rote textbook answers.

Once again, India enchanted me and returning reawakened those parts of the soul that are not always expressed in our more rational and ordered existence in Australia. Travelling with my husband and two boys made the visit even more memorable, watching the two golden haired boys be drawn into the hearts of so many people at the conference and the hotels and by strangers we met along the way. How can we know the impact this can have on a young developing mind.

Watching them respond to the challenges to their little world view makes me hopeful that these memories will be a strength for them in their lives.

I would encourage anyone to attend one of these Indian conferences at some time in their palliative care careers as they never fail to challenge and expand one's understanding of what is palliative care and how can it be provided in settings vastly different to our own. The next conference is in Delhi in February 2009, see you there?

**Odette Spruyt,
Melbourne**

Montreal Conference

The Montreal Conference on the Care of the Terminally Ill remains one of the most celebrated international conferences on the Palliative Care calendar. Indeed, its ancestry is significant. The founder of the Conference, Balfour Mount also first coined the expression "Palliative Care" in the mid 1970s. This Conference was the 17th of these bi-annual gatherings.

The range of presentations was very broad from evidence based medicine through to psychosocial and spiritual issues. There were special sessions on paediatric palliative care, palliative care in the context of Motor Neurone Disease, palliative care and the humanities, the treatment of dyspnea, the use and efficacy of topical opioids, ageing and geriatrics, loss and bereavement and international issues.

The Conference plenaries are always fascinating with past conferences being graced by the Dalai Llama, Stephen Lewis, the UN Special envoy on HIV/AIDS in Africa, the philosopher John Ralston Saul and the American Jesuit priest Father Daniel Berrigan. At this Conference the Plenary speakers included the philosopher Charles Taylor who spoke eloquently on "Multiculturalism and Spirituality in a Secular Age". He challenged accepted orthodoxy that we are living in a society that is uniformly secular and pointed to the universal nature of spirituality in all humans. He said that the modern Palliative Care movement was a good example within society of a discipline that recognised and managed the entire dimensions of the human person and was comfortable in the domain of spirituality.

Another plenary was co-presented by Kathy Foley and the United States Ambassador to Uganda, Jim Kolker. Kathy Foley has been a seminal figure in both pain management and palliative care around the world. She spoke on the multiple developments in advocacy for Palliative Care globally. Foley focussed on international developments in Paediatric Palliative Care and the significant challenges

that exist. She reflected on the significance of the WHO monograph on cancer pain management and Palliative Care in children in the mid -1990s as "a unifying force". The monograph clearly articulated that "nothing would have a greater impact on the quality of life of children with cancer than the dissemination and implementation of the current principles of Palliative Care, including pain relief and symptom control." The monograph strongly argued that paediatric palliative care should be involved from the time of diagnosis. She cited a significant paper (Liben S et al, Paediatric palliative care: challenges and emerging ideas. *Lancet* 2008;371:852-64) by a group that have constructed a paediatric palliative care model from diagnosis to death and bereavement that involves hospital, hospice, home and community care. Foley discussed palliative care as a public health context – preventing suffering, appropriate government policy, drug availability of essential medications and access to education. In addition she discussed the growing recognition and use of the concept of palliative care as a human right.

She described the "staggering" figures of the HIV/AIDS pandemic – 20 million people have died since the inception of the pandemic, 1.5 million children have died in the past 5 years, 2 million children under the age of 15 years are living with HIV/AIDS and 15 million children have lost one or both parents to the pandemic.

The US Ambassador to Uganda, Jim Kolker, spoke about his experience with advocacy and support of the government of Uganda in their struggle with the HIV/AIDS pandemic. Critical developments were reforming opioid laws to allow better availability of opioids for medical purposes and the development of government policies that placed palliative care and pain management as central to the public health of the population.

A fascinating forum was held by Linda Ganzini examining the experience in one of the few jurisdictions in the world which has legalised physician-assisted suicide – Oregon. The issues are complex and the studies show a wide variation of attitudes to this legal environment in health professionals, patients and their families. It is interesting to note that on the day of the US Presidential election the state of Washington voted in a referendum for physician – assisted suicide. It now joins Oregon as the only two states in the USA that have these laws.

Healing and whole person care was featured. Significant figures including Michael Kearney spoke on this topic. In 1992 he wrote a seminal article "Palliative Care – just another specialty?" He advocated then and since that the philosophy of Palliative Care should always reach beyond the core of symptom control into the psychosocial and spiritual dimensions. As he stated in

that article "If we fail to accept the view that there may also be potential in the suffering in the dying process ...if we sell out completely to the literalism of the medical model with its view that such suffering is only a problem ... we may become only symptomatologists within just another specialty. In essence we may be in danger of selling our soul to the very medical model whose excesses have created the needs our specialty sets out to meet." Kearney re- examined these thoughts in the light of developments in our specialty since 1992. He discussed the elements of whole person care, the nature of suffering and the role of health professionals in care of patients and their families.

A full day was devoted to the concept and utility of Palliative Care as a human right. Liz Gwyther, a Palliative Care Consultant in Cape Town, Richard Harding and myself have recently completed a monograph on this topic. A union of the Worldwide Palliative Care Alliance (WPCA), and the International Association of Hospice and Palliative Care (IAHPC) have actively promoted this concept and promulgated the Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights at the Conference in preparation for World Hospice Day which immediately followed the Conference. The theme of the World Day was "Palliative Care – as a Human Right."

Another highlight was a wonderful documentary by Sinead Donnelly, a Palliative Care Physician and documentary film maker from Ireland. This was the fourth documentary Sinead has made in the context of Palliative Care, place of death, bereavement and the role of community in the care of seriously ill persons. All four documentaries have been broadcast on Irish television. The presentation was in two parts – a qualitative presentation of the experience of patients and their families who die in hospitals and a documentary that was a beautiful insight into the experience of families of patients who die in hospitals. The presentations complemented each other perfectly.

Time and space do not allow me to canvas the breadth and depth of this Conference. I have attempted to touch upon some highlights. I have audio copies of the above talks and would be happy to make copies for any reader who is interested.

Frank Brennan
Calvary Hospital, Sydney

Journal Club

Using the Liverpool Care of the dying Pathway: Bereaved Relatives' Assessments of Communication and Bereavement - Veerbeek L et al, *Am J Hosp Palliat Care* 25(3):207-14 (2008).

Importance of the study:

A care of the dying pathway (CDP) provides both a registration system and a systematised interdisciplinary team (IDT) care plan (process) for managing patients thought to be in the terminal phase of their illness. Evaluation of the CDP process has so far largely been limited to documentation audits. Hence, compliance with the CDP process has been seen as a valid proxy measure for "benefit vs harm or neutral effect". This article is one of only a very few that outlines a study to measure meaningful outcomes of a Liverpool Care of the dying Pathway(LCP) process.

Study Questions:

- Does use of the LCP create a more positive retrospective memory of experiences of EOL communication in the last 3 days of life between professional staff and patient relatives?
- Does use of LCP decrease relatives' bereavement stress as measured at approximately 4 months post patient's death.

Study Design:

Population: patients' relatives, where patients had died in one of six participating Dutch institutions (hospital, nursing home and home care settings) in the previous two months. 70% of patients died of cancer and 30% died of non-malignant causes. There were two different cohorts of relatives: The Comparator Group (283) pre LCP (Nov 2003-Feb 2005). The Intervention Group (292) post LCP intervention process (Feb 2005-Feb 2006). Intervention: The LCP - a complex process that required education of all staff in the participating units. Once the LCP was introduced it was considered that contextual care parameters for the "terminal phase" had changed. Outcomes measures:

- Communication perception: VOICES (Views of Informal Carers Evaluation of Services), a validated NHS postal questionnaire, was used to measure retrospective views of communication and comprehension by relatives of information given at EOL.

- Bereavement status: the Leiden Detachment Scale (LDS), a 7 question scale based on an "attachment theory" approach, was used to measure bereavement stress.

- The questionnaires were both sent out at approximately 4 months post the patient's death. Collated results for all willing cohorts of relatives in each group (pre & post LCP use) were then compared.

Main results:

- Communication: there was a measurable beneficial effect on EOL communication and comprehension. However, this was not statistically significant.
- Bereavement: Two variables were shown to be significant: being the spouse rather than any other relative of the patient and the introduction of the LCP process

Critical appraisal of validity:

- Patients were not randomised as all 6 settings wanted to implement the LCP process. Instead, two separate cohorts were used: pre LCP and post LCP patient relatives.
- Results were obtained from only 59% of Cohort 1 (pre LCP) and 55% from Cohort 2 (post LCP) relatives.
- The two cohorts were fairly similar (the LCP was only used in 44% of Cohort 2 patients). It was felt that under the "intention to treat principle" the training in using the LCP was a sufficient "total care change" however. This may have in fact diluted the results and lowered the effect size.
- Blinding was not possible.

Limitations of study

- The group of relatives who did not participate (41% & 45%) might have had significantly different communication memories and bereavement stress levels.
- The validity of the LDS (based only on attachment theory). An alternative, more broadly based bereavement measure such as the Adult Adjustment to Grief scale may be more meaningful when measuring bereavement stress?
- Is a 2 point change in bereavement score clinically significant as well as statistically significant?
- Some hospital patients were only on the LCP for 16 hours prior to death.
- Sub-group analysis of results was not done comparing groups.

**Rohan Vora, Gold Coast
Queensland**

Conference Update

RACP (NZ Branch) Annual Conference

Date: 4–6 November 2009

Where: Hyatt Hotel, Auckland, New Zealand

NZ Societies of Internal Medicine, Geriatric Medicine and Palliative Medicine

Trainee's day at Auckland City Hospital on Tuesday 3rd November

Together! 2009

International Conference on Cultural Connections for Quality Care at the End of Life

Date: 24-28 September 2009

Venue: Perth, Australia

For more information: www.palliativecare.org.au

11th World Congress of Psycho-oncology

Date: 21-25 June 2009

Venue: Vienna, Austria

For more information:

<http://www.ipos-society.org/professionals/meetings-ed/congress.htm>

6th Annual Paediatric Palliative Care Symposium 2009

Date: Friday 6 March 2009

Venue: Lorimer Dods Lecture Theatre, the Children's Hospital at Westmead

For more information:

<http://www.chw.edu.au/prof/education/>

or Education Centre: (02) 9845 2091



ANZSPM members enjoying the Darwin Conference