

ANZSPM

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EDITORIAL

Dear all,

Christmas is on the horizon yet again.

This edition brings contributions about the recent successful 7th National Palliative Care Conference in Adelaide, a reflection from Sandy Macleod while doing a locum in a strange land and notices about an interesting conference on opioids in UK. And there is of course the 6th ANZSPM Conference in Auckland in September 2004, which will be combined with the 16th New Zealand Hospice Palliative Care Conference and a tribute to our former member Bob Pye who sadly died prematurely and in tragic circumstances.

The AGM of our society was held during the PCA conference in Adelaide in September 2003. Seventy-two members attended. Topics of discussion included the need for a formal secretariat to professionalise our society and take the burden from already busy professionals, our relatively new role as the special society to the Chapter of Palliative Medicine and medical workforce issues in different parts of Australia and New Zealand. Our membership numbers are stable and the finances of the society are currently healthy. You will all see a new subscription notice soon with credit card payment facilities. All as a result of a new database that has been recently completed.

Our New Zealand membership is also stable and important issues for them include a National Palliative Care Strategy, a new Hospital Palliative Care NZ Group and of course intense planning for the ANZSPM Conference next year.

With best wishes for Christmas and the New Year

Greg Crawford

Adelaide, December 2003.

PRESIDENT'S SOAPBOX

ANZSPM members will no doubt have seen the Service Planning Guide recently released by Palliative Care Australia. It is one of the most useful national public documents to be released in this country because it actually bites the bullet and maps out the level of staffing and resources required to deliver specialist palliative care as an integrated service across community and inpatient settings. It also contains an innovative and challenging public health agenda. This recognises that it is only by grasping a true public health approach that we will be able to engage the public we serve in a process of improving care and decision making at the end of life.

It has also been encouraging to hear of the road map which is being established with the key stakeholders concerning access to drugs used in palliative care which are currently unavailable on the PBS. This represents a great deal of hard work by many, notably Peter Ravenscroft, David Currow and David Woods. ANZSPM has been represented by David Brumley at these joint therapeutics meetings. No doubt all of our ideal drug availability lists would vary slightly and the initial list may be relatively unexciting, but there is promise of more progress now that the process has been established and the issue of palliative care drugs is registered with the relevant government agencies. If you wish to raise anything to do with this subject, please contact us and we can pass comments and questions on to the group.

Those of us who research and use ketamine hope that it will soon be possible to improve access to this drug in the community. At present the funded options for patients with opioid resistant pain are limited, and mostly require inpatient admission, or access to a sympathetic hospital pharmacy. As we learn more about drugs for refractory pain there will be increased need for community access, if unwanted admission to hospital is to be avoided, especially for rural patients.

The second round of NH&MRC palliative care grants has been advertised. Although the timing of the process at the end of the year is unfortunate, the possibilities for research in the field are now substantial and more enduring than ever before. It is good to see that the parameters are now wider and more clinically relevant.

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The biennial PCA meeting in September in Adelaide was obviously a big success. When I got there on the Friday morning for our AGM everyone was talking about the dinner-dance the night before. It says something about either the enduring power of The Beatles (which is unquestionable), or the demographics of our field that it was so popular. Plans for the ANZSPM meeting next year in Auckland are now well underway with Brian Ensor and colleagues. Members are encouraged to support the meeting by submitting papers, and planning to go.

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At our last council meeting we had more discussions about the administration of our society and the need for a paid secretariat or membership services contractor. Discussions are underway with potential providers of such services and we hope to resolve this issue soon. We feel that there are real limits to our growth and activities in a voluntary organization of already very busy people. If we are really to advance the cause of palliative medicine in all its guises and settings, and the medical contribution to end of life care and symptom control in its broadest terms, we need to have the infrastructure and access to paid staff to do the work. There are particularly promising possibilities for our role as the recognised special society for palliative medicine at the RACP, and on a recent trip to Sydney I had useful initial discussions with the new College CEO about this.

As the year comes to an end I would like to thank all of our members for their input, the Council for their work and support, especially David Brumley (Secretary) and Pat Treston (Treasurer), and Janis Keogh my Administrative Assistant at McCulloch House for their hard work in keeping ANZSPM functioning during 2003.

I wish you all a happy summer, joyous Christmas season and all the best for 2004.

Michael Ashby
Melbourne, December 2003.

**THE 7TH AUSTRALIAN
PALLIATIVE CARE CONFERENCE,
ADELAIDE CONVENTION CENTRE,
SEPTEMBER 9-12, 2003**

"TIME TO REFLECT"

The 7th National Palliative Care Conference, held in Adelaide, in the characteristic balmy Adelaide spring weather and the congenial hospitality of Adelaide was a huge success on many counts.

The numbers of registrants was a record 1006, with 82 from outside Australia, 37 known indigenous delegates and at least 155 medical practitioners. The theme "Time to Reflect" challenged us all to consider our reasons for working in this area of care and to take time to look back. There was a very strong indigenous theme. This was a specific program that ran through the conference and was extremely well attended. The overseas keynote speakers were Allan Basbaum from San Francisco, Colin Murray Parkes from London, and Connie Dahlin from Massachusetts. Other plenary speakers included Linda Kristjanson from Perth, Malgosia Zobllicki from Brisbane and Brian Kelly who is now in Sydney.

There was a wonderful program of the arts, as one would expect from the culture capital of Australia. A wonderful musical welcoming ceremony from the indigenous owners was memorable, setting the atmosphere for the next three days. Introductions to plenary sessions with live music as well as Reflection Times with wonderful photography were most moving. The conference had the cherubs of the Anglican Cathedral choir at the start and the jazz band from Marryatville High School - a public specialist music school - to keep the farewell drinks buzzing at the close. There was a reception in the Adelaide Museum, a guided tour by the Anglican Archbishop of Adelaide of "The Art of Death" and nothing has yet been said about "The Beatal" at the Conference dinner, kindly sponsored by Mundipharma. There were a few "over-exerted" delegates on the final morning! Some danced the night away.

Mary Brooksbank, her committee and all who worked so hard to make this conference such a resounding success are to be congratulated. Well done.

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CLINICAL PRACTICE GUIDELINES FOR THE PSYCHOLOGICAL CARE OF ADULTS WITH CANCER

A joint publication from the

National Breast Cancer Centre

and the

National Cancer Control Initiative

NHMRC Approved April 2003

If you would like to receive a copy of the guidelines please call the National Breast Cancer Centre (NBCC) on free call (Aust) 1800 624 973. Alternatively, complete the form below return by mail, fax or email.

Name: _____

Position: _____

Department: _____

Organisation: _____

Address: _____

Suburb: _____

State: _____

Postcode: _____

Phone: _____

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National Breast Cancer Centre, Locked Bag 16, Camperdown NSW 1450

Free call: + 61 1800 624 973 fax: +61 2 9036 3077 email: director@nbcc.org.au

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THE TOP END FROM THE 'BOTTOM END'

Medical tourism is a privileged means of professional adventure and cultural exploration. A five-week locum at Territory Palliative Care, Darwin during the 'dry' season allowed me an escape from the snows of the Southern Alps of New Zealand and to experience this magnificent chunk of Australia.

It came as no surprise to me that the multidisciplinary team of health care professionals practising palliative care in the Top End are similar to those who got rid of me for a few weeks - talented, dedicated, skilled and humane. The pathology of our respective patients differs little, though I was struck by the huge incidence of hepatocellular carcinoma in the Northern Territory, about twenty-five times the national rate. The malignant combination of hepatitis, alcohol and aflatoxin (found in stored cereals) is as damaging for the Territorian as are the holes in the ozone layer for the pale pakeha Cantabrian. The young average age of the Northern Territory, thirty-three, is paralleled in the youthfulness of the palliative care caseload which I calculated to be sixty-five. Only recently, perhaps because of air-conditioning, have people stayed to retire thus few aged-care facilities exist. Frontier males significantly outnumber females and this has implications for home caring of the dying. As yet Darwin has not built its much-promised purpose-designed hospice, thus, sadly, long sojourns in the Royal Darwin Hospital eventuate. Though not ideal, coming from the Australasian hospital with possibly the longest running acrimonious medical-administration conflict, I greatly appreciated the friendly, co-operative and most expert care this hospital provided. It reminded me of how we used to practice medicine in an environment focusing on the sick and not only on the dollar. The Royal Darwin Hospital is not a bad place to be sick in, as the survivors of the Bali bombings testify. The lack of local radiotherapy facilities in the Northern Territory however continues to be a source of inconvenience. Hopefully the architect who designed the 'new' Royal Darwin Hospital, with window shields to prevent falling snow accumulate, has by now retired. He has proven (once again) to me that it is people and not buildings that make health care.

There are in another's patch always clinical idiosyncrasies to discover. I had never considered that tropical houses often have wickedly steep external stairs, which are a nightmare for the frail to climb, or that Fentanyl patches may slip on a sweaty body. Territorians know about hydration, those reminders are not necessary, but I wondered if because of this, relatives struggled a little more to allow nature and thirst to determine (de)hydration near death. Life stories are richer than those in

novels and Darwin boasts fascinating tales of escape (from the south, from wives and maybe the law), boys' adventures and confrontation with the harsh, hostile and hot environment. Recent cosmopolitan immigration and a feminising of the Territory add to the already extraordinary local history of Japanese bombings, cyclones and legalised euthanasia. One of the rewards of medical practice, for me, is that I get live history lessons each day, and there are some 'beauties' in the Top End.

The Northern Territory presents a probable future-world scenario - a globally warmed, generally affluent, alcohol drenched population, with insufficient aged-care resources and massive wealth and opportunity differentials, living in a harsh environment. The Northern Territory today may be like our world of the future. In this future Territory Palliative Care will continue to have its very important place in the sun.

With familiarity we tend to forget the inherent wealth and specialness of our homeland and become complacent about daily life. A stretch outside is invariably stimulating. Travel and OE (Overseas Experience), that indispensable part of antipodean culture, teaches one most about oneself. The inadequacies of Christchurch's disjointed and under-resourced palliative care services were blatantly apparent to me by having enjoyed an alternative. I have returned with new vigour to do something about them. This is not to say that all one experiences in foreign lands are comforting. As a Kiwi, and usually accepted as 'nearly' Tasmanian, and convinced that much of the 'ANZAC' spirit still prevails, I was severely challenged by my ignorance of the problems of indigenous health in Australia. Of the caseload about fifty percent were aboriginal patients (who comprise 30% of the Northern Territory population), though mostly they resided far away from Darwin. Terminally ill Aboriginal patients seeking a wheelchair to venture to the non-air conditioned and smoking-permissible hospital surrounds, recollections about the natural mother of a 'Stolen Generation' patient in renal failure, and the complexities of land, isolation, language, skin and clans enticed me to reflect upon my own race relationships and those of my country.

As I write I haul off the Internet an editorial entitled 'Palliative care needs of minorities' in the BMJ of 26 July 2003, a theme edition on Death, and also the BMJ edition on Indigenous People (August 23). New Zealand's race relations and our provision of health care to Maori and minorities would seem to me to be so different to that of Australia that I, raised in New Zealand and having lived much of my life here, can venture no

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THE TOP END FROM THE 'BOTTOM END'

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reasoned comment. Palliative Care must address cultural and access issues in the populations we serve; though the ways and means will be as varied as the cultures and the localities.

The New Zealand population (2001 Census) comprises of 14.1% Maori, 6.4% Asian and 6.2% Pacific people. Ten percent of Maori live in the South Island and my local iwi or tribe has nearly 40,000 persons. There are 350 million indigenous people in the world. Maori have a life expectancy 8-10 years less than the non-indigenous population. The health status gaps between non-indigenous and indigenous populations are slowly shrinking only in the United States, Canada and New Zealand. The differences are mainly attributable to circulatory conditions, external causes, respiratory disease, diabetes and neoplasms. The avoidable death rate, by for example lifestyle changes and therapeutics, for Maori is double of most Europeans. An increase of the responsiveness of conventional services and the establishment of dedicated indigenous programs are the directions of the remedial efforts. The current needs of the dying Maori patient and their family (or whanau) are not particularly well attended to by palliative care services. Mason Durie, a highly respected Maori academic and psychiatrist, believes in practice that conventional services and indigenous services can exist comfortably together. In the same BMJ, Tariana Turia, Associate Minister for Health, describes why and how Maori 'decided to take our health into our own hands' and to reject (much) of the conventional services. As only 5% of the NZ health workforce are Maori a complete, separate, apartheid health service would appear unlikely at this stage.

Health services in NZ are required to recognise the principles of the Treaty of Waitangi, an 1840 agreement that saw sovereignty exchanged for Crown protection. Because of the treaty, Durie states, Maori occupy a position that is not afforded other non-indigenous ethnic minorities in New Zealand; even where comparable standards of health exist. Administratively and legally sanctioned positive discrimination for Maori has encouraged a lessening of the social trench between the populations and easier racial relationships. The cost is the understandable evolution of a sense of entitlement by the favoured minority and a reactive resentment by (a minority of) the majority. The next phase of race relations in this country will concern how these issues are resolved and the ownership of the foreshore and seabed will likely be the playing field for this

debate. Health will remain a critical indicator and outcome measure of our race relations. If our provision of palliative care to the Maori population can be improved then reasonableness and not radicalism may prevail. Good quality shared services for all, irrespective of race, should result. Australia's problem, and the solutions, are and will be distinctly different to New Zealand's.

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2ND BRISTOL OPIOIDS CONFERENCE 26TH AND 27TH FEBRUARY 2004

Star-studded cast with Eija Kalso from Finland, Nathan Cherny from Israel, Jose Pereira from Canada, and of course Henry McQuay and Anthony Dickenson from the UK, and the line up from Bristol (Graeme Henderson, Max Headley, Karen Forbes and Andrew Davies).

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THE COCHRANE CANCER NETWORK

The Cochrane Cancer Network is part of the Cochrane Collaboration, an international organisation that aims to help people make well-informed decisions about healthcare. It does this by preparing and maintaining systematic reviews of the effects of healthcare interventions. The systematic reviews are published on the Cochrane Library, which is available on CD-ROM and via the Internet and is updated quarterly. As well as details of every Cochrane systematic review whether it is completed or in progress, the Library includes a database assessing the quality of non-Cochrane reviews (Database of Abstracts of Reviews of Effectiveness), a register of controlled trials and a methodology register.

The Cochrane Cancer Network (CCN) is a Field within the Cochrane Collaboration, which focuses specifically on cancer. The Network has assisted in the development of the 14 Collaborative Review Groups carrying out reviews covering 90% of cancers. Some of these groups are only concerned with a particular type of cancer such as the Lung Cancer Group or the Breast Cancer Group, whilst others are concerned with various diseases in an organ system that could include cancer, such as the Skin Group and the Ear, Nose and Throat Disorders Group. CCN supports each Collaborative Review Group in the preparation and maintenance of cancer related systematic reviews by: - searching for randomised controlled trials in cancer, promoting the work of the CRGs to find more reviewers, peer reviewers and consumers, helping the groups identify funding opportunities, producing the Cancer Library to ensure that cancer systematic reviews are made as widely available as possible.

The Cochrane Cancer Network is keen to forge links with cancer organisations worldwide in order to raise awareness about the work of the Cancer Network and the Collaborative Review Groups. It is particularly important that we continue to find committed individuals, who may want to carry out a systematic review, become a peer reviewer or offer consumer advice on reviews from a patient's perspective.

Please do not hesitate to contact me if you feel that you can collaborate in promoting our work.

I look forward to hearing from you.

Best wishes,

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For information on the Cochrane Cancer Network, visit the Cochrane Cancer Network's website, at www.canet.org

NEW WHO DEFINITION

Here are new definitions from the World Health Organization for Palliative Care and for Paediatric Palliative Care.

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

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OBITUARY

DR ROBERT 'BOB' PYE

(2/10/1952 - 7/8/2003)

Many of you will be aware that Bob died suddenly this year. He leaves behind his wife, Jo, and two daughters, as well as his extended family and many friends.

I first met Bob 12 years ago when I joined the Silver Chain Community Palliative Care Service. As my team leader, Bob took me under his wing and became my mentor and good mate. His knowledge of palliative care was then unparalleled as was his enthusiasm and dedication to improving palliative care services in Western Australia and Australia. Bob was one of the leading doctors for the Silver Chain Palliative Care Service and helped in formulating and implementing many of their policies that still remain in operation. He was also involved in the development of the Cancer Foundation Cottage Hospice (Perth's only stand alone hospice). Moreover, he served the palliative community at the Murdoch Hospice and headed the Palliative Care team at Joondalup Hospital.

With colleagues from Australia and New Zealand (we won't mention the rugby!), he helped to establish this august organisation, ANZSPM, and successfully recruited many of us in W.A. He was the inaugural treasurer, Newsletter editor and Western Australia's representative. Bob's role in palliative care was recognised when he was made a Foundation Fellow of the Chapter of Palliative Medicine. Bob's drive helped push the frontier of palliative care in Australia, as did his constant advocacy for patients to have the best available treatment. His attendances at national and international conferences ensured this.

As a doctor, his devotion to his patients was extraordinary. For most of us it is exhausting working 9 - 5 with the terminally ill but Bob ensured he was available for his patients 24 hours a day, 7 days a week.

Bob was a natural leader who led by example and often with the rich, somewhat black humour that exemplifies our service. His appreciation of fine wine was, for many of us, an added bonus.

Bob's influence will be ongoing and of perpetual benefit to those of us who knew him and continue to be inspired by him.

A wonderful doctor and tremendous friend.

Dr. Chris Jacklyn

MBBS, BMedSc, FRACGP, FACHPM

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making
contacts



Joint ANZSPM &
16th Hospice New Zealand
Palliative Care Conference
16 – 18 September 2004
Sky City Convention Centre
Auckland, New Zealand

JOINT 6TH ANZSPM & 16TH NEW ZEALAND HOSPICE PALLIATIVE CARE CONFERENCE AUCKLAND, NEW ZEALAND SEPTEMBER 16-18, 2004

You will have all received the First Announcement and Call for Abstracts with the last edition of the ANZSPM Newsletter. Visit www.hospice.org.nz for more details.

The theme of the conference is "Making Contacts". Keynote speakers include Ned Cassem from Massachusetts, USA, Stephen Schug from Perth, Rosalie Shaw from Singapore and John Ellershaw from Liverpool, UK.

Ned Cassem is a professor of psychiatry and a Jesuit priest. He has been significantly involved in the ethics and care of the dying and has interests in issues of violence, gun control and sexual abuse. John Ellershaw has been involved in the development of clinical pathways in palliative care in the UK and is interested in palliative care service delivery and philosophy. Stephen Schug will be well known to NZ delegates as well as now Australians. He is a former professor of anaesthetics in Auckland and is now in Perth, WA. Rosalie Shaw is originally from Australia and now leads the Asia Pacific Hospice Network and is in Singapore.

There are plans for an Aged Care/Palliative Care stream, a clinical lecture stream for GPs and Hospice Nurses and a wide variety of workshops and papers.

If anyone would like to invite one of the overseas speakers for a post-conference visit then the organising committee would be happy to discuss this further. Contact Brian Ensor nz@anzspm.org.au.

All in all it sounds to be developing into another conference not to be missed if at all possible. Start planning your leave and service cover arrangements, think about contributing. It will be interesting to see how combining with Hospice NZ might change the ambience and flavour of ANZSPM conferences.

For further information contact the Conference Secretariat:

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