Volume 10 Issue 1, May–June 2001

ANZSPM newsletter

ANZSPM
Australian and New Zealand Society of Palliative Medicine

Send Articles to: The Editor, ANZSPM Newsletter,
Dr GB Crawford
Southern Adelaide Palliative Services,
700 Goodwood Road, Daw Park SA 5041
if you prefer fax to: 08 8277 4957
Or use the web site: www.anzspm.org.au

EDITORIAL

New ventures are exciting but often tinged with some anxiety – often heightening the anticipation. I must say accepting the editorship of the ANZSPM Newsletter is such an experience for me. I am pleased to support the Palliative Medicine community at a time of significant change and challenge and am mindful of the competence of my predecessors. And I rely heavily on you who are ANZSPM.

I would encourage you to use the ANZSPM Newsletter and website. Flood me with letters, comments, articles and ideas. Visit the website. Print a report of your local members. Think who of your colleagues does not know about ANZSPM and might benefit by being part of this organisation.

This edition highlights recent activities of the ANZSPM Council – collaborative initiatives with RACGP, RNZCGP and ACRRM, and a draft position paper on Palliative Medicine. And an interesting paper from our UK equivalent organisation, the Association for Palliative Medicine, should provoke comments and comparisons.

Prof. Ned Cassem, the recent Glaxo Visiting Professor has toured Australia. I have always found this initiative beneficial. An interesting variety of world leaders in Palliative Care provoke stimulating thought and have been a focus for the Palliative Community in Adelaide to gather. This time was no exception. A delightful, personable, compassionate man, a psychiatrist, academic, clinician and Jesuit priest. His challenge was to maintain the human touch, to listen to the music as well as the words, to see the person we are supporting, to know their passions, aspirations and hopes. I particularly liked his concept of "an ego infarct." Takes a long time to heal.

I hope you find this edition relevant, stimulating and of interest.

The next edition will feature conference reports, book reviews and news of more ANZSPM activities. Don't miss it.

Greg Crawford
Adelaide
May 2001

PRESIDENT'S SOAPBOX

Our new Editor Greg Crawford has donned his top hat, leapt into the ring, cracked the whip and set the performers to work. John Cavenagh has taken up a position in the stands and will, I am sure, continue to make comments on performance as befits his status as immediate past editor.

You will be aware that palliative care has crept back into the news of late with events on both sides of Australia that have led to the usual array of poorly informed comment in the media. From participants in the debate about euthanasia come statements about the purported strengths and weaknesses of palliative care that we often neither claim nor accept. With input from members of the Council of ANZSPM I have written a rather long Draft Position Paper (Pages 6 & 7) which addresses some of the difficulties of describing what we do in our work – a task not amenable to a 20-second sound bite. It has helped me to clarify in my own mind what our role is as practitioners of palliative medicine and move on from being seen as a protagonist in the debate to living within our field of work. If described using the model of Venn diagrams, we work within the set of palliative medicine which includes a selection of practices and beliefs on the care of dying people but does not require us to express any opinion in the euthanasia debate. As individuals we all hold opinions on end of life issues which, amongst our members, range across the spectrum (albeit perhaps with a distribution different from the general population). However these sets of beliefs do not intersect with those that we are required to hold to practice palliative medicine effectively. Whatsoever happens to the debate and the law, we can continue to practice a palliative medicine which, with all its strengths, weaknesses and limitations, does not include euthanasia. I think that it is important for the community to know what they will get, and what they will not get, from palliative care. It may not meet all their wishes, but they need have no fear that we will foist onto patients that which they do not want. I take full responsibility for the Position Paper's deficiencies and I look forward to your comments. I hope that you find it useful.

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On a less controversial note, the Joint Position Statement on Palliative Medicine in General Practice has now been approved in principle by all three GP bodies. What I hope will be the final version is printed in the Newsletter for your consideration. Once that is confirmed we can move on to publicising the Statement and consider what further steps might be appropriate. Among the suggestions is that we develop a clinical Diploma of Palliative Medicine similar to the Diplomas of Obstetrics developed by the GP Colleges and the RANZCOG. Collaboration between RACGP, RNZCGP, ACRRM and FAChPM would be required if this model were to be followed. Obviously it would take a lot of work and may be some time down the track. What do you think we should be doing to develop palliative medicine in General Practice? Greg Crawford would be happy to print your thoughts.

At the same time that we work with GP bodies we are defining our relationship with the RACP. The College consults with a wide variety of specialised groups, the special societies, who meet as the Specialties Board of the RACP and bring expertise in subspecialty areas of medical practice. Like ANZSPM they include many members who are not Fellows of the RACP and, in some cases, not medical practitioners. The biannual meetings of the Specialties Board provide us with an opportunity to express our interests and opinions to the other special societies.

Our other nascent activity is the development of a relationship with the Health Policy Unit (HPU) of the RACP. This body looks at a variety of social and economic issues of importance to our communities and which may benefit from analysis and discussion. I feel that there is much that needs to be done both by the medical profession and the community at large to address our attitudes to death and dying, treatment choices, and the economic and ethical challenges of resource allocation. The HPU seems to be the best body that I have yet found to do this. Once we had raised this issue a number of other special interest groups related to the RACP, from neonatal paediatricians to oncologists, expressed an interest in joining the process. I am not sure where it will all lead but I don't think that it is a journey that we can avoid. Increasingly expensive technologies, our aging population, and the cultural pressure on doctors and patients for the continuing pursuit of longer lives confront the realities of our limited ability to pay. At the same time many people are expressing the desire for greater personal control and quality of life. We have probably all experienced circumstances where we have felt trapped with our patients on a treadmill of treatment with no easy way off. I hope that this process will lead to a much greater openness in the discussion of these difficult issues.

None of these processes are exclusive. Please contact me if you wish to become involved.

Up here in the North we are entering the most beautiful time of the year. Crisp clear nights (16°C) and warm dry days (28°C). The sparkling sea is lapping at the golden beaches of Magnetic Island and the sunsets are spectacular. Tempted? I will tell you more about the Townsville ANZSPM 2002 Conference at the Hobart PCA Meeting in September.

Will Cairns
ANZSPM President
Townsville
May 2001

LETTER TO THE EDITOR

Dear Colleagues,

I want your support to lobby Novartis to make Scop patches available in Australia. They seem to be available everywhere else in the world but Novartis inform me that there are no plans to make them available in Australia.

Scop patches are a very useful drug in palliative care and if sufficient ANZSPM members indicate their support, this can be used to lobby Novartis.

If you would like to see Scop patches used in Australia, please send me an e-mail to

RogerWoodruff@access.net.au

stating that you would like to see Scop patches reintroduced and giving your name and the names of the unit(s) with which you are associated.

Thank you.

Roger Woodruff
Director of Palliative Care
Austin & Repatriation Medical Centre, Melbourne.

ANZSPM WEBSITE

www.anzspm.org.au

Go there today. Check your contact details are correct. You will need your password. Print a report of your State or country's members.

Are there doctors interested in Palliative Care who are not there? Do they know about ANZSPM? Why not talk to them today.

ANZSPM – the special society for ALL doctors with an interest in Palliative Medicine.

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JOINT POSITION STATEMENT ON PALLIATIVE MEDICINE IN GENERAL PRACTICE

Australian and New Zealand Society of Palliative Medicine (ANZSPM)

Royal Australian College of General Practitioners (RACGP)

Royal New Zealand College of General Practitioners (RNZCGP)

Australian College of Rural and Remote Medicine (ACRRM)

"Palliative care is specialised health care of dying people which aims to maximise quality of life, and assist families and carers during and after death."

Palliative Care Australia, June 1999

Palliative Care has been defined in a variety of ways, but the above definition provides a simple and succinct description. The provision of Palliative Care involves a number of health practitioners who must work together, as a team, to provide the wide range of services required by patients and their families. For most patients, who spend most of their time in their homes in the community, this care is best co-ordinated by their general practitioner who should be equipped by training and experience to fulfil this role.

Many general practitioners find the care of palliative care patients and their families to be one of the most rewarding aspects of their practice although, at times, it can be difficult and challenging. All doctors should be acquainted with the principles of Palliative Care/Palliative Medicine during their undergraduate years, their time in hospital practice and in vocational training. The RACGP, the RNZCGP and the ACRRM all include Palliative Medicine as a core component of their curricula, and it is assessable. It may be difficult for individual GPs to acquire and maintain their skills in palliative medicine with only small numbers of patients and in the face of burgeoning education demands across the spectrum of medical practice. In order to care successfully for their dying patients GPs need access to Continuing Medical Education through a variety of media reflecting the diverse nature of medical practice in Australasia. There must be particular attention paid to the needs of rural and remote practitioners. In addition, all GPs should build links to, and obtain support from a network of regional palliative care services covering all of Australasia.

The Colleges and the Society believe that the provision of Palliative Medicine should continue to be considered as one of the core roles of general practitioners. General practitioners should be given, and are expected to assume, primary responsibility for the care of most dying patients in the community and can often continue that role in hospitals and hospices. To fulfill this responsibility general practitioners must be provided with resources and remuneration appropriate to the complex demands that effective Palliative Medicine imposes.

Most patients can be satisfactorily cared for by appropriately trained general practitioners with support and recognition from Specialist Palliative Care Services. General practitioners must also recognise that timely referral to these Services for assistance in the management of complex symptoms and psychosocial problems is entirely appropriate.

Editor

This is still a draft statement. Comments from members are welcomed. Put pen to paper and let us know what you think.

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PALLIATIVE MEDICINE MANPOWER ISSUES IN THE UNITED KINGDOM

CONSULTANT REQUIREMENTS IN PALLIATIVE MEDICINE

Recommendations of Association for Palliative Medicine Working Group, November 1999

Palliative care services continue to develop across the NHS and charitable sectors; not only is there close integration with cancer services and especially primary care, but also an increasing expectation that specialist palliative care should be available for patients with other progressive, terminal illnesses.

Palliative Medicine has steadily expanded and there are too few trained doctors to fill the advertised Consultant posts.

Prediction of future consultant numbers in the context of the evolving services is difficult. The Association has its own Manpower Data base developed from a workload survey of all Consultants in 1997, as well as information from the National Council for Hospice and Specialist Palliative Care Services Minimum Datasets. Our recommendation for Consultant numbers is based upon the present manpower figures, consultant activity and a cautious estimate in trends in referral patterns related to population base over the next 10 years.

The Consultant requirement is derived from the following estimates :

(a) Trends in referrals of patients with cancer.

Across the UK there is variation in proportion of people dying from cancer who are seen by specialist palliative care services. A range of 25-60% was shown in 1995 but this is clearly dependent upon availability of such services. The figure rises to over 70% of cancer deaths in areas where these services are well developed. As the aim is to ensure adequate provision of services to those patients who need them, a figure of 70% is used in our calculations.

(b) Trends in referrals of patients with non-cancer diagnoses.

A significant change has been the increased involvement of specialist palliative care for patients with other progressive, chronic diseases in response to Department of Health concerns about inequity. Currently these account for a small proportion of patients admitted to palliative care units (up to 10%), but more are seen by palliative care Physicians working in hospital teams. Current trends suggest that referrals from the non-malignant population are likely to rise further but it is impossible to judge the eventual figure. In these calculations, it is estimated that the additional numbers will be approximately 20% of the number with cancer - a figure currently seen by some hospital services.

(c) Number of new patients seen each year by Consultants.

From the APM workload study, consultants in palliative medicine spent nearly 40% of their time in non-clinical activities, particularly in supporting palliative care service development in both community and acute sector. Together with clinical worker cross hospice, hospital and domiciliary services, 97% considerably exceed their contracted sessions. However, it may be possible for each full time consultant to see up to eight new referrals per week over a working year of 45 weeks (comparable to the 7 new referrals per week recommended by Clinical Oncologists).

(d) Influence of a predominately female workforce.

Palliative medicine has proved to be an attractive specialty for women who comprise 50% of the current consultants and 77% of those in training. A significant number choose to train flexibly, thus extending the duration of training, and subsequently work less than full-time. At the time of the 1997 survey, 27% of the consultants worked part-time with a median of 6 sessions; the current consultant workforce is therefore smaller than the total of individual numbers and is closer to 210 EFT across the UK.

Calculation of Consultant Requirements

RCP baseline 80,000 resident population = 218.6 cancer deaths per annum.

If 70% access specialist palliative care = 153 referrals per year.

Add estimated non-cancer referrals (20%) = 184 referrals per year.

Consultant requirement if 1 EFT sees 360 new patients per year = 0.51 EFT.

Whole UK (58.8 million residents) = 375 EFT.

Current UK manpower = 210 EFT

Shortfall = 165 EFT

Additional Consultants needed (assuming 30% will work part time) = 215.

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We feel this is a minimum estimate, because it does not take into account:

- rising incidence of cancer in an aging population
- further increase in referrals with non-malignant diagnoses
- implementation of the National Service Framework for cancer services, which is increasing the workload for specialists in palliative medicine in cancer centres and units
- rising proportion of consultants working part-time
- academic posts, which are few in number but increasing.

Clearly, consultant expansion of this magnitude would need to be spread over a number of years and would be constrained by the availability of trainee doctors, and a limited number of suitable training posts and funding shortfalls. However, until it is achieved, there will continue to be wide geographic variation in the availability of specialist palliative medicine to patients and excessive workloads for the existing consultants.

Editor

Here is your opportunity to comment about the Australian relevance of this UK document produced by the UK Association for Palliative Medicine.

Visit the APM website: www.palliative-medicine.org

DIARY DATES

Palliative Care: Learning to Live
11 - 14th Sept 2001
Hobart, Tasmania.
Palliative Care Australia
www.pallcare.org.au

ANZSPM 2002 Conference
Townsville, Queensland
September 2002

PALLIATIVE CARE FORMULARY WEBSITE

WWW.PALLIATIVEDRUGS.COM:
A palliative care formulary on the internet.

Palliativedrugs.com is a site providing information about the use of drugs in palliative care for health professionals, particularly doctors, nurses and pharmacists involved in the care of patients with cancer. It is has been developed from the successful book, Palliative Care Formulary (Twycross, Wilcock and Thorp (1998) Radcliffe Medical Press, Oxon, UK) that has sold over 17,500 copies.

The site was launched in the UK in November 2000, over 1,500 professionals have already become members and the site receives 150 visitor sessions each day.

Although some of the site content is specific to the UK, it contains information that will be useful to all practitioners. It is envisaged that other country specific versions will follow in the near future including Australia, Canada, Holland, New Zealand, Portugal and Sweden. The version for Australia is being developed in conjunction with Professor Peter Ravenscroft and Dr Jenny Schneider. That for New Zealand by Dr Bruce Foggo and Mrs Anne Denton. The information contained on the website will be complemented by book and CD ROM versions.

The site is free to browse and use but full access to all of its facilities requires the completion of a registration process. Registered users will have access to the contents and search facilities together with a bulletin board to allow help and advice to be given and received to and from other colleagues about drug-related issues. A monthly email update newsletter containing the latest news about the use of drugs in palliative care is also offered.

We are grateful to Janssen-Cilag, Link and Napp Pharmaceuticals who have agreed to sponsor the site and so cover the costs of providing this service for health professionals. The drug information content of the site, however, is produced independently.

Dr Robert Twycross DM FRCP FRCR,
Sir Michael Sobell House, Oxford, UK
Dr Andrew Wilcock DM FRCP, Hayward House,
Nottingham, UK

Professor Peter Ravenscroft MD FRACP, FFPMANZCA, FAChPM,
Newcastle Mater Hospital, NSW
Dr Jenny Schneider BPharm PhD,
Newcastle Mater Hospital, NSW

Dr Bruce Foggo MB ChB FRNZCGP FAChPM,
St Joseph's Mercy Hospice, New Zealand
Mrs Anne Denton MPHC (pall. care) MPS ANZCP,
New Zealand

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DRAFT POSITION PAPER

THE PRACTICE OF PALLIATIVE MEDICINE AND PALLIATIVE CARE – WHAT IT IS THAT WE DO AND WHAT IT IS THAT OUR PATIENTS CAN EXPECT

Palliative Medicine is that discipline of medical practice specifically addressing the needs of patients who have illnesses which are causing their health to deteriorate progressively, and often rapidly, towards death. It comprises the medical component of Palliative Care, a multidisciplinary area of health care. The aim of palliative care is the relief of symptoms, the maintenance of the best possible quality of life for the patient, within the limitations of the illness, and support for the family before and after the death of the patient. Patients and their families are usually introduced to palliative care when it becomes apparent that attempts at cure are no longer possible or appropriate. However, from the time of diagnosis of a potentially life threatening illness, or even from the time of suspicion of such an illness, patients and their families may face emotional and existential issues commonly addressed as part of palliative care.

The application of the principles of palliative care should be a component of the practice of all medical practitioners. All doctors are exposed to the practice of Palliative Medicine during their training, and it remains a significant part of the day to day responsibility of general practitioners, oncologists, and many other doctors. Worldwide there are a growing number of physicians who specialise in the practice of Palliative Medicine. Formal training in the specialty of Palliative Medicine is now available through the Royal Australasian College of Physicians (RACP) or the Australasian Chapter of Palliative Medicine of the RACP. Although recognised in the UK and soon to be recognised in New Zealand, Palliative Medicine is not yet formally recognised as a specialty by government in Australia. An application for recognition is imminent.

Specialist palliative medicine is practiced within the context of a multidisciplinary palliative care team who bring a wide range of skills to patients in all venues of care (home, nursing home and hospital). No one doctor can acquire the skills to manage all problems faced in palliative care. We can only fulfill our role as practitioners of Palliative Medicine by working together with our colleagues on the multifaceted problems experienced by our patients and their families.

All specialist practitioners, be they palliative medicine physicians, nurses, airline pilots or electricians, set boundaries which define their field of practice. At the same time almost all fields of human endeavour accept that there are gray areas of uncertainty, and palliative medicine is no exception.

The following goals and principles in the care of people dealing with life-ending illness and death define the boundaries of the practice of Palliative Medicine as part of Palliative Care:

- Control of physical symptoms (e.g. pain, nausea, constipation, breathlessness)
- Management of mood disorders (depression, anxiety) and cognitive failure (confusion, delirium, dementia).
- Support in dealing with the practical difficulties caused by declining physical function and independence.
- Support for patients to explore the spiritual issues that are important to them.
- Support for the patient and their family in dealing with the issues of death, loss, grief, bereavement and existential distress generated by a life-ending illness.
- Support for rights of the patient to make decisions about their own life from the choices that are available. These include the right to refuse or withdraw from life-prolonging or life-sustaining treatments.
- Ongoing provision of palliative care to the patient until the time of death, and for the family through bereavement, regardless of choices that they may have made.
- It is not the aim of palliative medicine to either prolong life or hasten death, although either outcome may be an unexpected, or less commonly, a possible outcome of actions taken in pursuit of the points above. It may not be possible to know if either may have occurred given the uncertainty of the prediction of life expectancy. Such happenstance is part of all medical practice.

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The Palliative Medicine community includes members with the full range of views on the complex end of life issues currently being addressed in our community. Most would agree with the following points:

- Most patients receiving palliative care are enabled to die with dignity and are acceptably comfortable for the majority of the time that they are unwell.
- Many patients use the time while they are receiving palliative care to explore a variety of issues in their own philosophical and/or religious life, and in their relationships with family and friends. This can be very satisfying and rewarding both for the patient and their family, and help lead towards a peaceful death for the patient and peace for their family.
- Palliative medicine, while very effective in the relief of distress, does not claim to be able to control all pain or other symptoms.
- Even when physical symptoms are relieved, some patients continue to suffer significant distress due to philosophical, spiritual, emotional and psychological issues that may not be amenable to relief.
- The decision by a patient to refuse, or withdraw from, a possibly life-sustaining or life-prolonging treatment does not constitute euthanasia or suicide.
- Some patients, even though they may be experiencing no particular physical or emotional distress, wish to control the timing of their death.
- Doctors are not absolved of the responsibility to offer and provide ongoing palliative medicine regardless of the choices that patients may make. Nor can palliative care services refuse access to their support because such decisions have been made. At the same time, practitioners of palliative medicine can not be expected to venture outside the boundaries of the practice of palliative medicine, nor to act outside the dictates of their own conscience.
- All patients must be given access to appropriate symptom-relieving drugs. The risk that administration of such medication, carefully and expertly administered, will accelerate death is unlikely to be as great as previously believed, or as commonly stated. Any such risks, or the risk that the drugs will be used for purposes for which they were not intended, must be carefully weighed against the distress for the patient and their family if effective drugs are withheld. Risks are part and parcel of all areas of medical practice and all decisions carry risks, including decisions not to intervene.
- Unintended and unexpected outcomes are unavoidable when dealing with illnesses that often have highly variable and unpredictable courses. The discussion of these issues with patients is one of the responsibilities of medical practice.
- Doctors have a duty to act in the interests of their patients, but within the law, within their own ethical and moral framework, and within the commonly held values of their community. These imperatives can sometimes be in conflict.
- No patient should have their choices driven by a lack of access to high quality Palliative Medicine as part of Palliative Care services.

Most of the practice of Palliative Medicine in the delivery of Palliative Care is fairly straightforward. However at times there can be conflict between these principles and the wishes of individual patients, their families or other significant people in their lives. There can also be differences of opinion between palliative care team members. The disagreements that arise must be aired in the knowledge that resolution and consensus will not always be possible.

Practitioners of Palliative Medicine do not have the option to walk away from their duty to offer palliative care or refuse to bring their skills and experience to bear on the problems faced by dying people and their families. Actions outside the parameters described above, such as euthanasia, are not part of Palliative Medicine or Palliative Care. It is crucial that patients, their families and the community feel secure in the knowledge of what they can and cannot expect from practitioners of Palliative Medicine.

Dr Will Cairns
President
On behalf of the Council of the Australian and New Zealand Society of Palliative Medicine.
May 2001

Editor

Will has thrown down the gauntlet. Swamp me with comments, criticisms and accolades. Put pen to paper or fingers to keyboards.

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ANZSPM COUNCIL MEMBERS

Name	Office	Address	Phone/Fax/Email
Dr William Cairns	President	Palliative Care Service Townsville Hospital Townsville Qld 4810	Phone: +61 7 4781 9607 (w) Fax: +61 7 4781 9560 Email: president@anzspm.org.au
Dr David Brumley	Secretary	Gandarra Pall Care Unit 102 Ascot St Sth, Ballarat Victoria 3350	Phone: +61 3 5320 3895 Fax: +61 3 5230 3763 Email: secretary@anzspm.org.au
Dr Sarah Pickstock	Treasurer	Palliative Care Unit Hollywood Private Hospital Monash Ave, Nedlands Western Australia 6009	Phone: +61 8 9346 6372 Mobile: +61 419 854 161 Fax: +61 8 9346 6404 Email: treasurer@anzspm.org.au
Dr Greg Crawford	Newsletter Editor	Southern Adelaide Palliative Services 700 Goodwood Rd Daw Park SA 5041	Phone: +61 8 8275 1732 Fax: +61 8 8277 4957 Email: editor@anzspm.org.au
Prof Michael Ashby	Member of Council	McCulloch House Monash Medical Centre Clayton, Victoria 3168	Phone: +61 3 9559 5347 Fax: +61 3 95505344 Email: vic@anzspm.org.au
Dr Anne MacLennan	Member of Council	67 Balfour St Wellington New Zealand 6002	Phone: +64 4 389 2729 Fax: +64 4 389 2730 Email: nz@anzspm.org.au
Dr Paul Glare	Member of Council	Dept of Palliative Care Level 2, Gloucester House RPAH Missenden Rd Camperdown New South Wales 2050	Phone: +61 2 9515 7755 Fax: +61 2 9515 7464 Email: nsw2@anzspm.org.au
Dr Paul Dunne	Member of Council	Repatriation Centre Hampden Rd Battery Point Tasmania 7004	Phone: +61 3 6222 7332 Fax: +61 3 6222 7334 Email: tas@anzspm.org.au
Dr John Cavenagh	Member of Council	Division of Palliative Care, Newcastle Mater Hospital Locked Bag 7, Hunter Region Mail Centre Warabrook New South Wales 2310	Phone: +61 2 4921 1954 Fax: +61 2 4921 1952 Email: nsw@anzspm.org.au