

ANZSPM

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EDITORIAL

Here is the final issue of the ANZSPM Newsletter for 2002. We have a new Council - there are new faces around the table, Welcome to Brian Ensor, the NZ President, Pat Treston from Brisbane who has bravely accepted the challenge of treasurer, Graham Hughes from the Adelaide Hills town of Mt Barker and David Woods now from Launceston (but recently from country WA).

And we have just had a most successful conference in Townsville. Thank you particularly to Will Cairns and Louise Welch for their generous Far North Queensland hospitality. Will Cairns' unending support and activity for ANZSPM must be acknowledged. We wish him well in his new endeavours with the Chapter of Palliative Medicine in the College of Physicians.

Your Society is at a critical time. Our new President, Michael Ashby, clearly articulates the challenges ahead for all of us. We have administrative challenges (Why are so many of you non-financial?); we have constitutional issues (Should we have State representation? We have country representatives but no state representatives for WA, ACT or NT.); we need to know what our role and function clearly is and be an effective force.

This Newsletter, I hope, will provoke some thought and even action. Graham Hughes is opening the discussion about General Practice. Contact your local Council member, write to the Newsletter, have your say.

And the end of the year approaches with remarkable velocity. Surely it was only April a few week's ago! I do hope that 2002 has been a good year for you and wish you all the best for 2003.

Greg Crawford

Adelaide, November 2002.

PRESIDENT'S SOAPBOX

I am honoured to have become your new president and look forward, together with the new council, to serving the membership over the next two years. I want to thank my predecessor Will Cairns and outgoing council members for their contributions. Will in particular has worked tirelessly for ANZSPM, and I wish him well in his new leadership role with the Chapter. He and his group can also be very pleased with the well-organised, enjoyable and enriching meeting, which they ran in Townsville in September.

ANZSPM is the only body in Australia and New Zealand that can independently advocate for palliative medicine: both as a discipline, and as a group of practitioners, of whatever background and training. It is recognised by the RACP as the special society for the specialty of Palliative Medicine in Australia and New Zealand, an important role and responsibility. It is a small member-driven organisation run by elected volunteers in a national arena full of bigger players with better resources and professional offices. It is also apparent to many that ANZSPM is searching for purpose and focus since the inception of the Chapter of Palliative Medicine within the Royal Australasian College of Physicians in 2000.

The new council has been installed, including myself as president, without election. Whilst this might seem comfortable, it is not healthy for a membership-based organisation. I hope that at the end of this term we will be faced by opposition from an engaged and active membership, and I will view this as a surrogate measure of the quality of our tenure (the other explanation of course would be outright incompetence!). The alternative would be to move more towards the model of an organisation like Greenpeace, where you pay your subscription, sign up to a broad policy agenda, and then let the core organisation drive the action. I would be surprised if this is what ANZSPM members want. However, pressure of work and lack of time can make this happen by default.

The new council has not yet met, and we are planning a teleconference before the holiday season.

(Continued from page 1)

At an informal gathering, those council members who attended the meeting in Townsville explored a number of important issues, which will need to be put to the full council in due course:

- David Brumley agreed to stay on as secretary, on the understanding that we would fund professional membership services support for his role. Those present enthusiastically endorsed this suggestion and were delighted by his willingness to continue. I would also like to say how much I value his support, diligence and wisdom. I hope also to have him act in an unofficial 'vice-presidential' role, and to take on an international/Asian relations portfolio (an aspect close to his heart).
- Pat Treston kindly agreed to be our new Treasurer, taking over from Sarah Pickstock. Many thanks to Sarah for her hard work in this often-thankless role.
- At present we do not have a constitutional requirement to have a council representation from each Australian state and. We would like to remedy this by co-option in the short term (especially from WA, ACT and NT), but in the longer term more state-based activities and structures might be explored. I am personally open to looking at affiliate status for the New South Wales Palliative Medicine Society in due course if this has wide support in that state.
- Our New Zealand councillor was not present (through no fault of his own, I do not think the message got through!). We need to be continually aware of our cross-Tasman role, and of the different policy issues which are bound to arise in another country. We are delighted that New Zealand has achieved specialty status, and ANZSPM members are moving ahead with the necessary accreditation, quality and continuing professional development requirements in their country.
- We discussed at some length the purpose issue. I put the view that we needed to have a major focus on advocacy for those who do palliative medicine as their main specialist activity, as nobody else will. We all agreed that we needed to build on Will's efforts to endorse and support the role of General Practitioners in palliative care, both for those with a special interest, and the majority who simply wish to care for their own palliative care patients as the need arises. The latter group, however, probably do not look to ANZSPM to further their palliative care issues as they have far more powerful and effective channels through which to do this. Our new councillor from South Australia Graham Hughes is a GP in Mount Barker in the Adelaide hills.

He agreed to set out a suggested approach to General Practice issues, and his paper is printed in this Newsletter. It seems to me to be an excellent basis for future action.

- At present Palliative Medicine appears to be recognised de facto as a sub-specialty of internal medicine, but does not have wider recognition in its own right. Both of the formal RACP and federal Australian specialty status issues must be a major priority. Unfortunately the latter is subject to a new process which in my view is unnecessarily bureaucratic, time consuming, and expensive. We need to impress upon the relevant bodies the urgency of proper recognition of our specialty, an area in which we lag far behind the United Kingdom, and now New Zealand.
- We thought that we would try and meet in different locations around the countries, rather than just Sydney Airport (despite its obvious practical advantages), and try to coincide with other local professional or academic meetings.
- I also expressed the view that we might give some thought to planning future academic meetings in partnership with other colleges and societies (eg RACP, RACGP, RANZCA, RACR, APS, AGS, COSA, MOG etc). Palliative Medicine as a stand-alone discipline is a fragile enterprise, and collaboration seems preferable in order to promote vibrant inter-disciplinary cross-fertilisation on all aspects of end of life care and related issues.

I have had an interesting recent correspondence with Susan Newton in Newcastle. After seeing her letter in the last Newsletter, I sent her a copy of an article which I wrote in the Monash Bioethics Review (July 2002; 21(3): 12-14) about the Nancy Crick case. This has been produced here with kind permission of the editor Deborah Zion (see page 6). My purpose in doing so is to give you some idea of my personal thoughts on the subject. Our task on council is to walk a path between our own views and those of our members, which will be diverse, and sometimes opposed to our own. Both ANZSPM and PCA have tried to steer a tolerant and open course through this divisive issue, which keeps re-emerging in the public domain. I have always been very supportive of this tolerant openness, well reflected in my predecessor's contributions to this debate on our behalf, and keen to see the palliative care community avoid going headlong into battle against euthanasia activism. However, I do not doubt that a majority of our membership would like to see the peak bodies adopt a more clear opposition stance, and I am also sure that many would have similar feelings to those expressed by Susan.

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Please let us have your thoughts; preferably via the Newsletter and website so we can all participate. Susan Newton has also reminded us that she is Palliative Medicine sub-editor for the RACP Internal Medicine Journal. It is vital for us to make contributions to this journal to make the most of this excellent publication opportunity, and our recognition by the journal of sub-specialty status.

Lastly, we hope that you will all review your in-tray and that those who have not paid their subscriptions will rectify this. Nearly a third of our membership is non-financial, ultimately an unsustainable situation for any organisation.

My aim is for us to continue to build ANZSPM as a stimulating, supportive, reflective and relevant body. At the end of the day we all do this work because we know something of the needs of patients and families who face terminal illness. We recognise the necessity of dedicated and informed medical input into the work and processes of the multi-disciplinary palliative care community and the services it delivers. Whilst advocating for our discipline, the threshold question for any decision or policy is whether it helps patients, families and colleagues.

Michael Ashby

Melbourne, Oct 2002

PALLIATIVE MEDICINE LOCUM

Melbourne, Victoria

A locum is required in the Western suburbs of Melbourne to cover a palliative care physician going on maternity leave. The post is for 12 months starting end of February 2003 and comprises 0.6EFT.

Responsibilities include a 10 bed inpatient palliative care unit at Sunshine Hospital and an inpatient consultative service at Western Hospital. Additional clinical work is also available at Broadmeadows Health Service Palliative Care Unit.

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IMPROVING YOUR COMMUNICATION SKILLS RETREAT Adelaide, South Australia Wednesday 30th April to Saturday 3rd May 2003

A Rare Opportunity for Medical Specialists

A team of physicians renowned for their expertise in teaching Doctor / Patient Communication Skills and headed by James Tulsy and Bob Arnold (Project on Death in America scholars) will be conducting an intensive communications retreat in Adelaide. The retreat will provide an environment where participants can learn valuable skills and network with colleagues. The course will be solely for senior medical practitioners who care for patients nearing the end of life.

Further information: Courses Administrator

International Institute of Hospice Studies, 700 Goodwood Road, Daw Park SA 5041

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ANZSPM and GENERAL PRACTITIONERS

As a newly elected council member, it is evident to me that ANZSPM needs to determine its role, amongst other things, in relation to our General Practitioner members. As a GP, I offer the following thoughts for consideration and discussion.

Many thousands of GPs are involved with Palliative Care in some way or another, but only a small number are members of ANZSPM. I would not expect this number to increase significantly in the future, as only GPs with a special Palliative Care interest are likely to become members. It is therefore unreasonable to expect that ANZSPM will ever be a direct support or representative body for the average GP, who sees only a few Palliative Care patients in a year. GPs now see the Divisions of General Practice, (local, state and federal), as their prime support organisations, both for the purposes of political support and professional development.

Taking this into account, I see ANZSPM providing GP support on 2 levels.

In the first instance, direct support can be provided to GPs with a special interest and more involvement in Palliative Care by encouraging membership, and dissemination of information via newsletter, website and meetings. We need to recognise and support GPs who hold part time positions in Palliative Care units. Whilst these GPs may not have a specialist fellowship, their family practice background offers a unique and extremely important perspective and contribution to Palliative Care. It would be a backward step in my view to see these positions lost to GPs without specialist qualification, as more Palliative Care specialists come through the system. ANZSPM can continue to support the establishment and promotion of postgraduate studies in Palliative Care, (diploma courses etc).

Secondly, the much larger group of GPs who have only an average interest in Palliative Care can be supported by ANZSPM via the Divisions of General Practice. I believe we could have a resource/educational arm to our website, which could link to Division websites. General Practice has progressed spectacularly with regard to IT/IM over the past 5 years. Most GPs in Australia have a desktop computer with Internet access. It would be simple to link an ANZSPM page to Division websites. This page could list State resources in Palliative Care in addition to a page giving, for example, opioid conversions and syringe driver information. Once established, this link could be promoted through Divisions and changed if necessary. This would also provide easy email access for GPs to

contact local Palliative Care specialists for information and advice. This page could also provide information regarding postgraduate studies in Palliative Care, etc.

Remuneration has always been an issue for GPs in relation to Palliative Care. New Medicare item numbers for care planning and case conferencing have been designed to help in this area, but the complexities of these have been somewhat problematic. Models of care planning documentation and communication between Specialist units and GPs have been developed around the country, and our Newsletter could be a forum to share these models. Similarly, these models could be posted on the website for wider consideration.

General Practice training in Australia has now moved away from the RACGP, and is being undertaken by individual training consortia, under the direction of GPET (General Practice Education and Training). Some of the training consortia have expressed interest in their GP Registrars obtaining postgraduate diplomas in, for example, Palliative Care, during their training towards the FRACGP. Whilst this concept is in its infancy, an ongoing contact between GPET and ANZSPM would be useful and productive.

The face of Palliative Care has changed considerably with the recent formation of the Chapter of Palliative Medicine in the College of Physicians. I sense that ANZSPM is now trying to redefine its identity and role in this new environment. We need to be realistic and acknowledge that most of the energies will be directed toward the specialist interests. The GP support, however, to both our members and through Divisions of General Practice, is critical and needs to be affirmed. I strongly support the formation of the Chapter and specialist recognition, but GPs should not risk being disenfranchised in the process.

I am very interested to hear from any members, in particular GP members, who may have specific ideas regarding the role ANZSPM has in supporting General Practice. I will bring your ideas to council, and I hope to help keep ANZSPM relevant to us.

Dr Graham Hughes

General Practitioner, Mt Barker South Australia
Council member, ANZSPM
Chair, Adelaide Hills Division of General Practice
Board member, Sturt-Fleurieu GPET
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REPORTS OF THE BI-ANNUAL CONFERENCE OF THE AUSTRALIAN AND NEW ZEALAND SOCIETY FOR PALLIATIVE MEDICINE, September 2002

Key Note Speakers:

Professor Peter Maguire,

Director, Cancer Research Campaign Psychological Medicine Group, Christies Hospital, Manchester. UK

Dr. Gerri Frager,

Paediatrician and Medical Director, Paediatric Palliative Care Service, I.W.K. Grace Health Centre, Halifax, Nova Scotia, Canada

This was my first Palliative Care Meeting, and I have to say that it was a thoroughly enjoyable meeting. The environment of Townsville was warm and relaxing and I found the people attending the conference extremely friendly.

Will Cairns, as the President and Organiser of the Conference, was particularly welcoming. The sessions were good with a lot of emphasises on communication which is essential for all medical practitioners. The initial plenary session of Peter Maguire - "Dealing with Challenging Communication Situations" I found superb and took copious notes which I will be using in future for medical student lectures. Gerri Frager's plenary session "Life Threatening Illnesses in Childhood" was very moving and showed the strength of the individual that she is able to deal with these challenges in her every day life.

The Palliative Care Physician needs special skills in communication and I believe that this was evident in the meeting and also skills to help them deal with patients at this critical stage of their life. Good communication was evident throughout the meeting as was the support and care that Palliative Care Physicians feel for one another. The strength of this speciality, is the close ties required, as often the Palliative Care Physician will be working in a relatively isolated environment and needs to be able to access other people for support as needed.

The Conference dinner was relaxed and fun and I enjoyed meeting old friends and many new ones. Catching up at the last lunch also allowed us to continue the friendships with promises to meet again.

Well done to the organisers and I am looking forward to going to the Meeting in New Zealand in 2004.

Dr Penelope Briscoe

Deputy Director
Pain Management Unit
Royal Adelaide Hospital

We were very privileged to have Professor Peter Maguire at the recent conference in Townsville. Peter is a key figure internationally regarding communication skills for health professionals, both in terms of teaching and research. I have wanted to attend one of his workshops for some years and was very pleased to have the opportunity to do so close to home. It was great to see Peter in action during the conference workshop - he is a very skilled facilitator. I was impressed at his ability to handle such a big (~60 people) interactive group with a wide range of opinions regarding how things should proceed. Peter asked one member of the group to act the role of a palliative care 'patient' with psychological concerns; Peter played himself as a Psychiatrist. He asked the group how he should proceed at various points along the way, tried it out and then asked the group and finally the 'patient' for feedback. One issue that caused a lot of debate was whether Peter should mention to the 'patient' how much time was available for the consultation. I think some people were surprised that the 'patient' in fact quite valued this information.

I was lucky enough to also attend the pre conference 1-day workshop for local practitioners "Training the teachers of communication with patients who have advanced cancer". In this workshop Peter gave an overview of how he runs basic communication skills workshops and the evidence base for this. He did a similar role-play with one person acting the part of the 'patient' and himself the health professional. There was a lot more time for feedback and to explore the effect of using different techniques.

I was hoping that attending this conference would save myself a trip to the UK to attend one of his workshops there. However, it only served to whet my appetite for more. There is only so much ground that can be covered in a short workshop on communication skills. I am convinced that there is nothing that can replace being in the hot seat and then getting constructive feedback.

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In the 3-day workshops in the UK there is apparently a lot more time for individual feedback.

In the plenary sessions Peter gave an excellent overview of how to manage challenging communication situations and improving the psychological care of patients in palliative care.

At the various social gatherings for the conference I discovered that he is also a charming fellow with an infectious laugh.

Overall I thoroughly enjoyed the conference. It was well organised with interesting and useful sessions, an excellent opportunity for networking and of course a very relaxed setting.

Josephine Clayton

PhD student, Medical Psychology Research Unit,
University of Sydney

Part-time Staff Specialist, Sacred Heart Palliative Care Service

As a Paediatric Palliative Medicine Specialist, I was delighted that ANZSPM invited Gerri Frager as a keynote speaker to the 2002 conference in Townsville. Young children and teenagers are rarely the patients of most ANZSPM members, but they may well be the immediate family of patients who turn to you for advice on how to communicate their illness and prognosis.

Gerri is a paediatrician and the Medical Director of the Paediatric Palliative Care Service at the IWK Grace Health Centre in Halifax, Nova Scotia, Canada. She is Assistant Professor at Dalhousie University. Gerri came to this position having explored various models of palliative care delivery through a year-long travelling fellowship covering the US, the UK, and Canada. She then spent 2 1/4 years as a fellow with the Pain Service at Memorial Sloan-Kettering Cancer Centre in New York. She worked as nurse for 9 years before pursuing her medical degree at McMaster University in Hamilton, Ontario whose model of tutorial-based, self-directed learning is being replicated across North America.

Gerri gave two plenary lectures:

1. Life Threatening Illness in Childhood
2. Getting comfortable with paediatric pain and symptom management

And one workshop:

Tough talks with Children:
as patients and as family members.

In the first lecture she gave examples of how palliative care in paediatrics often needs to work alongside what most Palliative Medicine specialists may regard as significant intervention. The case she discussed regarding a teenage girl with end-stage Cystic Fibrosis who could not give up her hope of living to be a mother left few dry eyes in the room, a clear example of how terminal illness in children is a particularly emotive issue. Gerri's innovative "what if/ just in case" approach to that situation is certainly applicable to many situations in all areas of palliative care. To enable children/families (adult patients too) to maintain some hope, but concurrently consider "what if things don't go as we'd like them to"....this approach can open up wider discussions about specific goals that may be able to be achieved.

The workshop on tough talks with children stimulated discussion of past experiences of delegates and some guidelines on how to approach talks with children about death - either their own or that of a close family member. Focussing on the family's usual communication strategies, age of children and previous experiences as a basis for empowering parents to open the conversation with their children. The concept of a "dummy run" of the discussion to take place is a good framework for helping parents find the words they are likely to use in talking to their children. She also gave a list of resources for both professionals and families in the form of printed matter and useful websites.

In her final plenary lecture, Gerri outlined her approach to pain and symptom management in children with some simple guidelines and useful references.

In addition to the formal aspects of the conference there was ample opportunity for delegates to have informal discussions with Gerri about her approach to paediatric palliative care (and her experiences of Northern Queensland's Barrier Reef). Clearly the topic of palliative care for children has a particular significance to me (as I am currently establishing a Paediatric Palliative Care Service). However, I am sure most other conference delegates would share in my appreciation of Gerri's lectures, workshop and lunchtime discussions and thank ANZSPM for inviting her to speak.

Dr. Susan Trethewie

Staff Specialist, Paediatric Palliative Medicine
Sydney Children's Hospital
Randwick, NSW

Nancy Crick, Assistance to Die and Palliative Care

Monash Bioethics Review (July 2002; 21(3): 12-14)

Michael Ashby MD MRCP FRCR FRACP FACHPM MRACMA.

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For anyone who may have had cause to doubt it, modern public ethics debate is inherently casuistic, and narrative ethics have won the day. Gone are the days of grand over-arching principles, of faith, of political ideology, of public norms of conduct. The specific narrative informs the general. Rather as it used to be said that in order to get a road crossing installed you had to have a death at the place concerned first, 'causes celebres' advance ethical debate and put pressure on legislators to act.

This trend has had some positive outcomes. Firstly, it grounds the ethical discourse in practical everyday life, rather than in inaccessible ethical argument. Secondly, if you favour liberalism, then casuistry or narrative approaches tend to focus on the individual, by telling a particular story from which ethical issues are extracted and then argued about with a view to influencing public policy in the light of lived experience.

The recent public death of Queensland woman Nancy Crick rekindled the ever-smouldering embers of the euthanasia debate in Australia in a predictable manner. The same arguments were restated and the same interest groups mobilised in outrage until the public media attention span dissipated as it almost always does at the one to two week mark. 'What does it say about the value society places on human life when it adopts a procedure for legally terminating anyone's life?' asks Hugh Mackay 'Dignified death was her choice. Nancy Crick, after much suffering, has ended her life. She did not take this decision lightly. She tried palliative care and found it did not help her. She then made a decision, after careful consideration, to end her life.' Wrote a correspondent to the Age.²

What does Nancy Crick's story tell us?

It is hard to argue robustly about, or generalise from, the story of a courageous woman who faced her own death (not someone else's) and chose it in preference to her life of constant physical - and who knows how much mental - suffering.

She certainly appears to have had both a public and political death (alas for privacy, but it does limit what the rest of us can reasonably have to say). She recruited the assistance of a social action group (Exit), and the best known medical protagonist of euthanasia in the country, Dr Philip Nitschke.

All available testimony from family and friends appears to support the belief that this was what she wanted: namely, assistance to die with protection for those who rendered her such assistance, and to advance the cause by her own death.

The liberty issue at stake, namely her desire for the freedom to have help to end her life, seems hard, and maybe churlish, to argue with in the face of her persistence and courage. This writer can see no argument as to why Nancy Crick, the particular woman in this narrative, should not have had the assistance she so wanted.

However, on the down side for public narrative/casuistic ethics, it is not possible to do good clinical assessment in the media, and good ethics cannot be done in the absence of good facts. Clinicians, like lawyers, gather all the information about a patient, and then subject it to analysis. No such rigorous process can occur when the patient and/or family (very rightly) control the material released, and clinicians involved cannot and must not speak publicly about their patient, at least without permission. And it is wrong to argue over the incomplete clinical and personal detail of her story.

On the important issue pertaining to palliative care, no credible clinical assessment of her case can be made to ascertain whether palliative care could have achieved more or not. It was stated a number of times (as above) that palliative care was 'tried' as if it were some rigid package, deployed in a day or two and found to be wanting. For those of us who are in the game, her brief admission to a Gold Coast Hospital for palliative treatment was not enough and you cannot therefore infer anything about palliative care from this case.

Several very important themes familiar to pain and palliative care practitioners were on view here. Firstly, without the post mortem details, and, in particular, the microscopic tissue analysis results, it is not possible to say for sure that there was no cancer present. Indeed in bowel cancer it is well recognised that you can have microscopic disease infiltration of the abdominal contents, lymphatic and nervous tissue which fails to show up on scans or even at surgery. This infiltration can cause severe intractable pain. Secondly, the result of cancer treatment itself can cause ongoing physical and mental suffering, with disturbances to body functioning and body image. So active cancer recurrence is not the only cause of pain and suffering, and those in remission are not always happy, healthy and adjusted.

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Low weight, lack of energy, bowel dysfunction (eg diarrhoea, whether from 'twisted bowel' as reported, or not) and pain of perhaps uncertain cause would be enough to make anyone despair. Chronic pain, especially where no cause is found, is often poorly managed. Medicine, and its patients struggle with treating symptoms for which no clear objective cause has been found. Everything has to have a reason and a cause. But pain and palliative care medicine have to function and respond even when no cause can be found for the symptoms. Clinical work, like life, is messy. Evidence is now mounting in favour of the need to treat pain early and get on top of it in the first days or weeks, otherwise chronic pain mechanisms come into play and satisfactory control may be difficult or impossible to achieve. That's why multidisciplinary management, including psychiatric and psychological input, addressing the physical in the social, spiritual and emotional context, is necessary throughout the cancer journey.

NEW ZEALAND REPORT, November 2002

NATIONAL DEVELOPMENTS

1. NZ Cancer Treatment Working Party (NZCTWP)

As part of the overall NZ Cancer Control Strategy, the NZCTWP was formed last year to consider and develop issues concerning Cancer Treatment Services. It provides strategic advice to the Ministry of Health and District Health Boards regarding cancer treatment issues and formulates recommendations for implementation through working groups. The working party is made up of clinical representatives including palliative care, along with management and funding people and Ministry of Health agents.

Four working groups are considering: -

- Workforce issues
- Information and Clinical Data
- Drugs and New Treatment Technologies
- Radiation Oncology Facilities and Equipment

2. CaTSOP

As a by-product of this group, a Cancer Treatments sub-committee (CaTSOP) was formed by PHARMAC, the government's pharmaceutical regulation agency to assess applications for new pharmaceuticals used in the treatment of cancer and then to make recommendations to PHARMAC. The sub-committee includes 2 medical oncologists, 2 haematologists, 1 radiation oncologist, 1 palliative care specialist and a PTAC (Pharmaceutical Advisory Committee) member. This is likely to be involved mostly with new chemotherapy agents, but it will be good to have a PC voice in there.

Palliative care should not be in the business of appearing to tell people who say that their lives are not worth living that it has all the solutions and that they should live on no matter what. With due respect to those who attempted to help her, and of course to Nancy Crick herself, who knows whether anyone or anything could have been made her more comfortable /happy/reconciled to her circumstances. Tackle assistance to die by all means, but in a country where palliative care is not even recognised and funded as a separate medical specialty, and whole person integrated cancer care is a hit and miss affair, largely depending on where you live, the best publicly available evidence from the story of Nancy Crick suggests that there is much still to be done to improve care.

1. Hugh Mackay. Any legal killing degrades all life. The Age. 1 or 4 June 2002.
2. Letter to the Age 25 May 2002.

More specific to practical palliative care is the formation of another advisory group to PHARMAC, which is to review analgesic drugs. This group is chaired by Bruce Foggo, an ANZSPM member from Auckland and includes another 2 ANZSPM members, Jonathan Adler from Wellington, and Ross Drake, our paediatric palliative physician in Auckland. We have high hopes that this committee will improve our access to alternative opioids and possibly, adjuvants such as ketamine and gabapentin.

3. Education and training

CTA (Central Training Agency) has provided initiatives for training nurses and doctors in palliative care in NZ to support the PC Strategy. A Masters program in nursing was launched this year with central support. Registrar appointments have been funded in Auckland and Christchurch, and just, in Wellington. There are 3 training registrars currently and Kate Grundy as Chapter representative is working with CTA on a workforce survey to establish future training needs for NZ.

4. Nurse prescribing

Recent official publications on nursing have appeared suggesting that nurses want autonomous functioning, funded independently, and that there is international support for moves in this direction. Chairman of the NZMA, Dr John Adams, has pointed out that these papers have been developed without the input of the medical profession, and without debate as to whether they are the best way to spend limited funds or even a good direction to proceed.

Proposals for nurse prescribing in palliative care have been developing for nearly two years, without input from current prescribers, despite enquiries. We await their recommendations with interest.

5. The Hospital Palliative Care Interest Group

was born at the Special Societies conference last November. The group is separate from ANZSPM, as it is composed of nurses as well as doctors providing palliative care support to hospitals. 13 (of 27) people from around the country met in Wellington on 3rd May to discuss and initiate collaborative work on guidelines, minimum data sets and education and training - all specific to palliative care in the hospital setting.

6. APHN

NZ branch of ANZSPM has recently become a member of the Asia Pacific Hospice Network

CONFERENCES

2001

The Royal Australasian College of Physicians and Special Societies' Joint Annual Scientific Meeting, Auckland (30th Oct - 2nd Nov 2001)

ANZSPM(NZ) enjoyed its involvement in the RACP Joint Annual Scientific Meeting with Special Societies in Auckland at the beginning of November. ANZSPM took part as an official Special Society for the first time. Other societies represented were The Paediatric Society, The Internal Medicine Society of Australia and NZ and The NZ Geriatric Society. The theme was "Mind the Gaps: Transitions in Healthcare". Transitions from child to adult, living to dying and hospital to community were amongst those considered in various formats.

We were delighted that the first plenary session of the conference was devoted to palliative care. The session was chaired by Rod MacLeod from Wellington. Speakers were Michael Ashby, Sara Fleming (Paediatric Palliative Care Nurse Consultant, Adelaide), John Collins, and Michael McCabe (Director, NZ Catholic Bioethics Centre, Wellington). Apart from the plenary sessions each day, there were several breakfast sessions to choose from and a variety of workshops later in the day. ANZSPM had a well-attended workshop on non-cancer palliative care and multiprofessional teamworking, considering Motor Neurone Disease and Cystic Fibrosis as examples. Cathy Miller led another well-attended workshop on "Ethics through the Ages"; discussing ethical issues thrown up by selected cases from childhood to old age.

Michael Ashby and Anne O'Callaghan led the "Pre-dinner palliative care reflections".

A large audience gradually gathered (near the bar) to share in this contemplative session of poetry and prose, evoking a range of emotions and laughter.

Overall, this was a satisfying and enjoyable conference, with the opportunity to share a palliative care perspective with a wider audience of physicians (and vice versa). Huge thanks go to Anne O'Callaghan from Auckland who found herself on the organising committee and did a great job for ANZSPM.

2002

The annual *ANZSPM(NZ) General and Scientific Conference* was held on Waiheke again, at the end of February this year. Once more, we had over 30 doctors from around the country to share in the learning, networking and socialising. This is an important source of mutual support, especially for those working in relative isolation, or pressurised in various ways at their workplaces.

Hospice New Zealand biennial conference was in Napier, October 8-10. This is the NZ equivalent of PCA, with multiprofessionals and volunteers attending.

David Oliver is touring NZ in November following the Melbourne International ALS/MND Symposium, to talk about palliative care and motor neurone disease.

2003

ANZSPM(NZ) is meeting with the *Australian and NZ Pain Societies* in Christchurch March 9-13th. We are delighted that Geoff Hanks will be one of the speakers. Other overseas speakers include Steve Linton (Sweden), Edzard Ernst (Complementary Medicine, UK), Gerben De Jong (USA), Tore Eliasson (Sweden), Giancarlo Barolat (USA) and Keith Budd (UK). There will be prizes for best paper and best poster. Registration: www.apsoc.org.au

2004

The 6th Biennial Conference of the Australian and New Zealand Society of Palliative Medicine will be in Auckland, provisionally October 8-10th, at the Crown Plaza Hotel. ANZSPM will be joined by Hospice NZ, and supported by North Shore Hospice.

NZ COMMITTEE

The incoming committee comprises Brian Ensor, chairperson, Cathy Miller from Auckland and Warrick Jones currently in Southland, but moving to Northland. They may co-opt someone else from Wellington or South Island.

Anne MacLennan, Wellington, NZ

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n e w s l e t t e r

PSYCHOSOCIAL CARE OF ADULTS WITH CANCER

Earlier this year ANZSPM was asked to comment on the document described below. These comments, for which I take full responsibility, are quite direct but I think that they are fair in the light of our experience of patients who have undergone treatment for their cancer and eventually come to receive palliative care. Will Cairns, Townsville, 30/9/02

Comment on the "Draft for Consultation of Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer"

This creation of this Draft document is a very useful step to the improved psychosocial care of patients with cancer and their families. The palliative care and palliative medicine community have long played a major role in the psychosocial care of patients as they approach their death, in the support of their families, and in encouraging a healthy attitude towards dying amongst health workers and the community in general.

Most often our contact with patients has occurred, as it should, later in the course of illnesses. By this time most people have been dealing with the issues raised for them by their disease, including their possible death, for some time.

We believe that there is one fundamental weakness in the document as presented - it includes almost no discussion of the fact that many people die from their cancer and that this is an issue for patients from the moment of diagnosis, even in diseases with a high probability of cure.

Chapter 1 - Introduction and Background

In Section 1.1 there is no mention that one impact of cancer is death. It is not until p.4 in section 1.2 that there is any mention of mortality and only then as part a discussion of the evidence used to develop the Guidelines. The next mention of death is in Section 1.4 p.6 as part of a discussion of the stresses on health workers dealing with dying. There is no mention that death is also a stressor for patients.

Chapter 2 - Understanding the Challenges of Cancer and How People React

In the Introduction and Sections 2.1, Emotional and Social Issues, and 2.2, Psychological Issues there is only one single use of the words death (p.12), dying, dead, or die. The only other reference to the possibility that someone might die is in the subsection section on suicide (p.23). The possibility of death does not begin to be explored to any significant degree until Section 2.5 as "Towards-the-end-of-life issues". It seems that even this choice of words as a title is an attempt to avoid having to use "d" words, although they are not entirely absent from this section.

The Glossary definition of palliative care makes no mention of the

fact that palliative care patients die.

Whilst it is obviously important for health workers to sustain hope when appropriate, patients themselves usually consider the full range of possibilities from the time that they first think that they might have a life threatening illness. The language that we use, and the words that we don't use, set limits on the issues that we allow patients to explore as they deal with their illnesses. In our work in palliative care and palliative medicine we spend the majority of our time addressing the psychosocial issues raised for patients who are approaching their death. However these issues do not just start when patients and their families are told that a disease will be fatal. Often we find that they have not been discussed earlier in the course of their illness, even though many of the range of psychosocial problems that are described in these Guidelines are generated by the fact that patients and their families are dealing with the consequences of a possible death. (Is a patient anxious because of the cancer itself or because of the possible consequences of the cancer, such as death?)

The Guidelines should openly address the uncertainties of probability and chance inherent for patients with cancer. Patients are aware of the risks of dying and are affected by them from the very first stages of their illness.

There should also be a place in the Guidelines for encouraging the use of Advance Health Directives (or their equivalent depending on State legislation) as well as other therapeutic and end-of-life patient decision making options to further encourage increased patient participation and autonomy. The restoration of a sense of control over the choices that are there to be made can help to relieve emotional distress.

When I was in General Practice I had as a patient a young woman who had Ca-in-situ of the cervix. Even though she knew that she had virtually a 100% likelihood of cure, she was still fearful that she might die and would not see her children grow up. For patients with more serious illness these risks are far greater and must be addressed openly from the outset. We do not betray patients or undermine their hope by allowing them to raise issues of death and dying, however we do not serve them by blocking them from doing so.

The Council of ANZSPM thank you for the opportunity to comment on this Draft. We feel that it would fall short of its goals if it does not openly address the issue of mortality that is raised in the minds of patients by the diagnosis of their cancer. If we cannot address these issues we cannot expect our patients to do so.

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n e w s l e t t e r

BOOK REVIEWS

Michael Barbato, *Caring for the dying*

ISBN 0.07.471214.4

RRP A\$34.95

Available from Booksellers or McGraw-Hill Book Company

Brian Pollard, *The principles of palliative care: an introduction*

RRP A\$9.00

Available from the author. Email: brianjpollard@bigpond.com

These two books have passed across my desk in the last month. Both with specific audiences in mind and worthy of consideration as an aid for teaching students or providing a guide for carers.

Michael Barbato has produced a 250-page book aimed at people caring as the title says, "for the dying." Although this may not be politically correct (the phrase seems to now be "people living with a life-limiting illness"), it well describes the purpose. It is aimed at more end-of-life care.

This is a description of Dr Barbato's personal journey in life as well. It draws on his own life experiences and also uses short case examples. The writing style is flowing and pleasant but is pitched at the reasonably well educated. There are quotations from a wide range of sources that add colour to the narrative and I found provoked reflective thought.

This book covers the major issues of end-of-life care well. There is an introduction to the philosophy of palliative care and then discussions around pain and other symptoms, day-to-day care, time of death concerns and a treatise on bereavement and self-care. There is also a chapter on caring for a dying child and a chapter on Dr Barbato's area of particular interest - near death experiences, out of body experiences and deathbed visions.

This is a book to read, to reflect on why you work in palliative care, to recommend to well-educated carers and those searching for more intellectual support and is certainly a book for medical students and junior medical staff to read.

Dr Brian Pollard has written and published a 44-page booklet designed as "something simple" to read for medical students about palliative care.

This is a small volume that covers the philosophy of palliative care, physical and emotional symptom issues and provides a dialogue about communication. Themes of honesty, respect and dignity are explored as well as a brief discussion on patient

choices and the law and end-of-life decision-making.

This small text is a very brief introduction to the concepts of palliative care and fills a useful position in our growing literary resources.

C Warfield, H Fausett (Editors), *Manual of Pain Management*, 2nd edition

ISBN 0.7817.2313.2

Lippincott Williams & Wilkins

A Berger, R Portenoy, D Weissman (Editors), *Principles and Practice of Palliative Care and Supportive Oncology*, 2nd edition

ISBN 0.7807.3324.3

Lippincott Williams & Wilkins

Two second edition texts have also sat on my desk in recent months. Both are texts of well-respected American researchers and practitioners. The Manual of Pain Management is a good general pain text covering the advancing knowledge of neurophysiology, with chapters on pain by anatomical location and by common pain syndromes. This is a useful text for updating theoretical knowledge of current pain issues.

The Principles and Practice text is a competitor of the Oxford Textbook of Palliative Medicine. It is a hefty North American tome with an eminent editorial team who have brought together experts in the relevant areas that one would expect to find in such a reference book. The focus and outlook is unashamedly for the USA. The chapter on Models of Palliative Care, I found particularly interesting. It commenced with a quote, "Palliative care is a vast wasteland in American medicine, and nowhere is it less well understood or more neglected than in the academic health science center." and then described what is currently happening. There are real developments and it is interesting to see how palliative care has grown within a different framework.

This is a reference text. It is a weighty and worthy addition to your reference library, accepting that it is aimed at the American scene. It is not light bedtime reading.

Greg Crawford

1. Rowe JW. Health care myths at the end of life. Bull Am Coll Surg 1996; 81:11-18

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