

Contents

A note from the editor	1
President's report	1
New Zealand Branch Chair's report	2
ANZSPM's Memorandum of Understanding with the New Zealand Branch	4
Palliative Care Outcomes Collaboration (PCOC)	4
Rapid pharmacovigilance in palliative care	5
International Working Group on Death, Dying and Bereavement	6
Churchill Fellow explores international palliative care volunteer models	8
An interview with Frank Brennan: Incoming President of ANZSPM	9
Why, why and why? The three most important questions in the clinical practice of palliative medicine	10
Palliative care development in Malaysia: 'Well, I guess I asked for it!'	12
The 70th anniversary of the death of Lou Gehrig	14
A letter to Aafje	16
Positions Vacant	18
Conferences & Events	20

ANZSPM

PO Box 7001
Watson ACT 2602
T 0458 203 229
F 03 8677 7619

President: Frank Brennan
Newsletter Editor: Natasha Michael
Executive Officer: Marita Linkson
All email: executive@anzspm.org.au
Website: www.anzspm.org.au
ABN 54 931 717 498

A note from the editor

ANOTHER YEAR DRAWS to an end and it is a time for many of us to reflect on the events of the year; progresses and changes within our professional and personal lives. I embarked on my own personal journey to Australia 18 months ago and am grateful for the many new bonds of friendship and collegiality. Strangers are now dear and valued friends, new roots, ties and a new place to call home. We celebrate the essence of all of this at Christmas.

In this edition we welcome Frank as the incoming president of ANZSPM and thank him for *sharing his story*. What a wonderfully productive year for ANZSPM and our specialty. I thank **Marita** for her outstanding work, warm friendship and many laughs, and all of you for your many contributions.

For 2012, we will embark on a 'Spotlight on the State/Territory' series where we will focus on palliative care developments in individual states and territories. We will be seeking contributions from individual services. Tell us your stories; share with us your successes. The newsletter belongs to you.

Finally, we wish you the peace, love and joy of family and friends this Christmas.

Natasha Michael
Editor



President's report



By Frank Brennan
President

I WOULD LIKE to commence this, my first report as President, by paying tribute to my predecessor. **Phillip Good** has been an outstanding President—clear, creative and tireless in his work for ANZSPM. His presidency has seen a continuation of the structural changes commenced under the presidency of **Odette Spruyt** and a significant increase in the activities of the Society and the reach of its membership. At a personal level, Phillip has been especially generous to me with his time and advice throughout this period of transition.

Continued on page 2 ►

ANZSPM

◀ Continued from page 1

President's report

As Phillip stated in his final report, ANZSPM relies absolutely on the interest and involvement of its members and we are delighted with the response to ANZSPM activities and the continuing applications for membership. Those activities have included, over a three-year period, the ANZSPM Fora and, in 2011, the Palliative Medicine and Surgical Update. The feedback from these events has been uniformly positive and certainly indicates the need for—and interest in—education for doctors working in our discipline. We plan to hold the Palliative Medicine and Surgical Updates every two years, on alternate years to the ANZSPM Conference.

Preparation continues for the ANZSPM Conference for 2012. Its theme shall be *Collaboration in Palliative Care*. It shall be held in Queenstown, New Zealand on 4–7 September 2012. Further details shall follow in time.

After considerable work from many members, a formal Memorandum of Agreement between ANZSPM and ANZSPM Aotearoa (the official new name for the New Zealand Branch of ANZSPM) was signed in October. I want to especially say thank you for the work of **Cathy Miller**, ANZSPM Aotearoa Chair, and her Executive members for their work towards the completion of this document which formalises the nature of the relationship and the respective roles and responsibilities of the main organisation and its New Zealand Branch.

As President I look forward to picking up from Phillip's work as the ANZSPM representative on the Council of Palliative Care Australia (PCA) and welcome any input ANZSPM members have in this regard.

In addition, the other ongoing relationships that will continue to be important for ANZSPM will be the Chapter of Palliative Medicine and the Adult Medicine Division within the College of Physicians.

I would like to take the opportunity in this report to thank **Marita Linkson**, the Executive Officer of ANZSPM, for her wonderful work. Marita has worked tirelessly for the Society in assisting the President and Council in their work, organising the regular teleconferences and face-to-face meetings of the ANZSPM Council, organising the multiple ANZSPM Fora held in two countries, improving the Society's website, preparing the logistics that allow for membership to be renewed on-line, the coordination and preparation of the ANZSPM e-Updates, and coordinating the response by the society to the multiple enquiries and calls for submissions and replies from government and non-government bodies. This is constant and unrelenting work and we are very indebted to Marita for this work.

Finally, a vote of thanks to **Natasha Michael** for her work as the editor of this newsletter. We have been delighted with the care and preparation that has clearly gone into each issue. I would encourage all ANZSPM members to contribute. In our locations we are all distant from each other and this newsletter is a

great way of being connected to other doctors practising palliative medicine.

I look forward to seeing and meeting with you in my time as President. Please do not hesitate to contact me if you have any thoughts or concerns.

You can read more about Frank Brennan in our interview on page 9.

New Zealand Branch Chair's report



By **Cathy Miller**
NZ Branch Chair

ANOTHER YEAR HAS flown by, a very busy year for the NZ Branch of ANZSPM (ANZSPM Aotearoa) with lots of national activities in the palliative care sector. It has been quite hard scurrying along trying to keep up with it all! Currently our Executive Committee (EC) comprises: myself – Cathy Miller (Chair), **Sinead Donnelly** (Deputy Chair), **Sara Rishworth** (Treasurer), **Amanda Landers**, **Christian Robold**, **Ian Smiley** and **Peter Kirk**, and co-opted members **Carol McAllum** (Palliative Care Council [PCC] nominee) and **Lee Anderson** (Trainee Rep). Below is a month-by-month recap of the activities the EC has engaged in this year.

In **January** we beavered away organising the Annual Meeting planned for Wellington in April. This took a considerable amount of

Revised publication schedule for ANZSPM Newsletter

IN ORDER TO meet timelines for publishing, the editorial team have revised the publication schedule for the ANZSPM newsletter. Commencing in 2012, the newsletter will be published in March, July and November. Closing dates for submissions will be end of February, end of June and end of October respectively.

EC time, and we are writing some resources/templates to guide future meeting organisers. There is no great urgency, as no annual meeting is planned for 2012. Instead we encourage members to pencil in the ANZSPM conference in Queenstown 4–7 September 2012, a 'must-attend' event, with guest speaker **Fliiss Murtagh**, who has written widely on managing patients with end stage renal failure.

In **February** we formalised a link with the Palliative Care Council, who not only endorsed the ANZSPM statement on euthanasia (see ANZSPM website) but who also host a link to ANZSPM on their website. Likewise we now link to theirs.

In **March**, we were advised that member **Rod McLeod** had been appointed as a member on the Palliative Care Advisory Group (PGAG), which advises the Ministry of Health (MoH). This group is chaired by another of our members, **Ross Drake**. Neither is on the EC, and neither represents ANZSPM *per se*. Rather they are representatives in their capacity as experts selected and appointed by the MoH. With no formalised reporting lines from this body back to our Society, the onus is on us to keep abreast of developments, which we have worked hard to do.

The National Palliative Care Data Business Process Standards were released by the Health Information Standards Organisation for feedback. I had provided feedback on an earlier draft and members were advised of this opportunity for direct input.

In **April** a very successful Annual Meeting was held, organised largely by **Sinead Donnelly**, with a number of invited speakers. The meeting gave the EC a clear message that it was time to find a national voice and to contribute more, as an organisation, to the development of Palliative Medicine/Care in our country. The EC has been working

towards this goal and **Christian Robold** is drafting a development plan that will soon be released to members for feedback.

Christian and I have also written to and commenced meeting with key people in the palliative care sectors (see below). Members at the Annual Meeting also supported a formal translation of our name into Maori, and ANZSPM Council has supported the use of the term *ANZSPM (Aotearoa)* as an interim measure.

In **May** we were asked to put forward a candidate for the gynaecological cancer guidelines group; **Amanda Landers** put her hand up for that task.

In **June** the committee discussed the Health Workforce New Zealand (HWNZ) blueprint for palliative care as set out on their website. We have written to them expressing our concerns that no opportunity has been offered to provide feedback. We await a response.

June also saw the release by the PCC of the *National Health Needs Assessment for Palliative Care, Phase 1: Assessment of PC need*, which we read with interest.

By **July** it became very clear that the EC has insufficient manpower to support its activities. **Marita Linkson**, our Executive Officer, already has as much work as she can manage, so in August we engaged **Fiona Liddlow** on a contractual basis to provide administrative support, primarily meeting preparation, recording minutes and handling correspondence. This has proved very helpful. Over time we expect it to reduce the load for EC members.

August marked the first of a series of meetings between the EC and those involved in national palliative care activities. **Christian Robold** and I met with **Ross Drake** and **Rod Macleod** to explore how ANZSPM (Aotearoa) could:

- Ensure inclusion in key stakeholder consultation particularly where policy development and strategic planning are concerned;
- Raise awareness of the interests of our membership;
- Communicate that members of our society work in a wide range of environments (including hospitals, hospices and general practice);
- Draw their attention to the ANZSPM strategic plan; and
- Communicate that our objective is to be the driving force of Palliative Medicine in Australia and New Zealand.

This meeting went very well. Further meetings are planned for December with **Simon Allen**, Palliative Care Advisor to the Minister of Health, **Saskia Booiman**, Senior Advisor, Cancer Programme MoH and **Mary Schumacher**, Chief Executive, Hospice New Zealand (HNZ).

Sara Rishworth took over the role of Treasurer from me in August, a great relief!

During **September** the MoH released the Advance Care Planning Guidelines and details were circulated to members. The Resource and Capability (R&C) framework was also circulated to members who were offered the opportunity to give us their feedback for collation into an ANZSPM response.

With varying views about the R&C framework within the EC, and without feedback from the members, we decided not to provide formal feedback on the document *per se*. We did however write to explain our reasons and express our ongoing interest in the matter. We were subsequently invited to send a delegate to a workshop in Wellington.

Continued on page 19 ►

ANZSPM's Memorandum of Understanding with the New Zealand Branch



It was smiles all around at the signing of ANZSPM's inaugural Memorandum of Understanding with its New Zealand Branch, in Sydney on 4 October 2011.

By Marita Linkson

FOR PRESIDENT FRANK Brennan, and NZ Branch Chair Cathy Miller, (pictured) it was the culmination of many hours' work, supported by ANZSPM's Council, New Zealand Executive and Executive Officer, and Cathy's husband Peter Hassell (a retired New Zealand solicitor, who donated his time to the initial draft).

The Memorandum of Understanding (MoU) sets out the nature of the New Zealand Branch's governance and the nature of the relationship between the Council and the New Zealand Branch Executive, and is a requirement under Clause 8.3 of ANZSPM's Constitution.



Palliative Care Outcomes Collaboration (PCOC)

PCOC ASSISTS PALLIATIVE care providers to improve patient outcomes by enabling their clinicians to accurately assess the quality of care they provide to their patients. PCOC obtains and reports on information regarding patient care and symptom management. This information supports clinicians in their treatment decisions, assists managers in their service planning and informs policy makers in funding and planning services. Participating palliative care services submit their datasets biannually to PCOC, enabling PCOC to develop service specific, state and national datasets. These datasets are analysed and reported to services, providing them with feedback on their performance, recognition of their achievements and opportunities for quality improvement.

Outcomes in Palliative Care Report 11 (January to June 2011) has been released to 100 palliative care services participating in PCOC. Data and analysis for each service is presented alongside the national figures for comparative purposes. Data are summarised and patient outcomes benchmarked to enable participating services to assess their performance and identify areas in which they may improve. During the reporting period, data were provided for a total of 13,885 patients who between them had 17,394 episodes of care and 38,363 palliative care phases. The national figures reflect all palliative care services who submitted data for the January–June 2011 period. A full list of these services can be found at www.pcoc.org.au.

PCOC welcomes Associate Professor Katherine (Katy) Clark, MB, BS, MMed, FRACP, FChPM as the PCOC Clinical Director. This is a conjoint appointment for Katy as she is also the Director of Palliative Care at Calvary Mater Newcastle, Area Director of Palliative Care for the Hunter New England Local Health Network and Associate Professor of Palliative Medicine at the University of Newcastle.

Katy has many years' clinical, academic and research experience in palliative medicine. She has a number of publications, particularly in her key research interest areas of constipation and dyspnoea, and has contributed to a number of textbooks. As a researcher, Katy is a collaborator with the Palliative

The MoU ensures that New Zealand members are clearly identified within the ANZSPM membership register, defines the means by which NZ membership fees are set, describes the makeup, method of election and powers of the New Zealand Executive, as well as the way in which ANZSPM supports and funds the New Zealand Branch.

The MoU is governed by the laws of New South Wales, the state in which ANZSPM is incorporated, and is to be reviewed annually.



ANZSPM would like to acknowledge the *pro bono* assistance provided by **SWAAB Attorneys** in reviewing and finalising our Memorandum of Understanding.

You can download a copy of the MoU from the Publications pages at www.anzspm.org.au.

Care Clinical Studies Collaborative (PaCCSC), where she is a chief investigator on a number of trials. Katy was recently successful in securing NH&MRC funds for a multisite study on constipation and a project on tele-medicine consultations in palliative care.

As the PCOC Clinical Director, Associate Professor Clark will consult mainly with the medical staff currently involved in PCOC and will also be available to consult with palliative care services considering joining PCOC. The Clinical Director will join with the National Quality & Education Manager and the National Director to form the PCOC National Executive.

For further information on PCOC please visit our website, www.pcoc.org.au or contact **Maree Banfield**, National Quality & Education Manager, on 02 4221 5965.

Rapid pharmacovigilance in palliative care

ACCURATELY ATTRIBUTING CAUSES to adverse drug reactions (ADRs) in palliative care is a challenge. For example, the fatigue and confusion associated with psychotropic medicines may be difficult to distinguish from clinical decline and be misattributed because of the assumption by clinicians, patients and their families that dying brings with it a collection of inevitable symptoms.

Information from randomised controlled trials can inform decisions about the efficacy of pharmacotherapy but some are insufficiently powered to detect rare adverse events or small but significant increases in the rates of more common adverse events. They also fail to select the sub-population at greatest risk of adverse events: the frail on multiple medications.

In this context, post-marketing surveillance is essential for monitoring the effects and safety of medicines used in clinical practice where diversity in rates of drug metabolism, gut absorption and motility and drug-drug and drug-disease interactions all contribute to the adverse effects profile.

In Australia, the Therapeutic Goods Administration (TGA) requires each sponsor of registered medicines to have an appropriate system of pharmacovigilance in place to ensure appropriate levels of responsibility and liability for its marketed products. However, regulatory authorities such as the US Food and Drug Administration (FDA), the European Medicines Evaluation Agency (EMA) and the TGA still rely on spontaneous reports of adverse effects from doctors and other health professionals as part of post-marketing surveillance, particularly for new drugs. This system has proved successful for the detection of adverse events for some medicines but it has important limitations. Increasingly, automated linkage data, patient registries, case reports and data from specific studies are being utilised under the rubric of post-marketing research, but not all post-marketing studies are limited to safety issues.

The principal aims of pharmacovigilance programs are:

- to improve patient care and safety in relation to the use of medicines, and all medical and paramedical interventions
- to improve public health and safety in relation to the use of medicines
- to contribute to the assessment of benefit, harm, effectiveness and risk of medicines, encouraging their safe, rational and more effective (including cost-effective) use
- to promote understanding, education and clinical training in pharmacovigilance and its effective communication to health professionals and the public.

A detailed literature search indicates that there is virtually no post-marketing surveillance in palliative care despite the wide use of medicines in that population and the knowledge that ADRs occur more commonly in older people and those on multiple concomitant medications.

Decline in the function of various organs involved in drug metabolism, storage and excretion can be a result both of ageing and disease progression and predispose patients to ADRs. The palliative care population particularly is vulnerable to adverse drug-drug and drug-host interaction given that physical decline is largely irreversible.

There are few data on the clinical characteristics of ADRs or patients' perspectives on their impact. While this has been studied in other settings data are lacking on ways to avoid ADRs in palliative care. An Australian study in an oncology patient setting further indicates that 48% of predictable ADRs were also potentially preventable.

There is a clear need to quantify the extent and severity of ADRs in palliative care, to inform intervention

Continued on page 20 ►

REPORTS

International Working Group on Death, Dying and Bereavement

By Odette Spruyt

The International Working Group (IWG) on Death, Dying and Bereavement was held in the Yarra Valley, Victoria, in late October this year.

THE MEETING FOLLOWED the two day symposia in Sydney and Melbourne with speakers drawn from this group, including **Dr Colin Murray Parkes, Therese Rando and Ken Doka**. The IWG is currently chaired by **Christopher Hall**, director of the Australian Centre for Grief and Bereavement who convened the meeting in Melbourne.

This was a meeting with a difference. The IWG is an invitational group with members participating for 30 years. They meet approximately bi-annually at sites dotted around the world. Most are self-funded and for some, it has evolved into a big family vacation every couple of years.

There is no pharmaceutical sponsorship. The IWG operates on a low budget; fuelled by friendship, collegial development, a desire to provide international leadership in the area of death, dying and bereavement, and to nurture the academic life of its members.

There were approximately 100 attendees, an international and eclectic mix of researchers, clinicians, and some who combined roles. The few palliative care medical IWG members present included **Dr Ben Zylicz**, now in Switzerland, and **Dr Scott Long** from Connecticut hospice (the first hospice in the USA). The first night of meet-and-greet is like a reunion of close friends but with a striking openness and warmth of welcome to new participants.

On the first night, participants convene to propose and determine the discussion topics which will in turn, determine the agenda of the week. Those topics which generated enough

interest were selected for discussion and participants self allocated to their preferred group. Groups then met eleven times for 1–2 hour periods during the week to share experience, expertise and stories and, for some groups, to develop a paper or an IWG summative document on that theme. Examples of discussion topics included *Ethical issues at the end of life*, *Finding meaning in dying*, *Bereaved children*, and *The language of grief*.

I chose to join the bereaved children group as I felt my adult-directed service could improve our care and awareness of the younger family members, who are often hidden or at least less visible in the caring group presenting to the cancer centre.

Our discussions centred around a proffered focus theme of 'Children do better when...' with examples as follows.

Children do better when:

- they have at least one caring adult in their world
- they are included (not excluded) and allowed to be involved
- they are treated as individuals with unique needs
- they are given access to truth
- they are given informed choice, within boundaries
- they have 'permission' to grieve (or not)
- their grief is validated.

These were then grouped into themes with plans to further this discussion at the next IWG meeting in Victoria, Canada.

Bereavement working group in thematic deliberation



Noteworthy to me was the group's avoidance of pathologising grief and the concerns expressed about the new DSM-IV classification, which is stimulating great debate in the death and dying academic circles.

Nancy Hogan, academic psychologist, and developer of the adolescent Sibling Bereavement instrument spoke of her findings which support the concept of 'continuing bonds' as effective adjustment to loss. This is in contrast to the promotion of ideas of 'letting go' and 'moving on'.

The first night of meet-and-greet is like a reunion of close friends but with a striking openness and warmth of welcome to new participants.

Irwin Sandler's Family Bereavement Program (FBP) research provided a very hopeful note in our discussions, especially to the parents among us. The program is based on a resilience framework that bereavement involves a process of adaptation, following tremendous disruption, which involves developing resilience rather than 'recovering from' the experience of loss. The program is directed at both children and parent/caring others. His message was that those responsible for parenting can be taught to parent better.

Both children and parents in the RCT showed objective evidence of benefit from this highly structured intervention compared to controls and that an immediate effect on improved parenting was apparent which appeared to be sustained at retesting six years later.



(Left to right): Sadako Tokumaru, Yoshiko Suziki and Chikako Ishii, Japan. These grief counsellors and educators from Japan spoke about the trauma experienced following the 11 March Japanese tsunami.

Many members of the group, including **Mal and Di McKissock**, were experienced children's grief counsellors. Imagine sitting at the 'kitchen table' with experts from around the world, prompting them to share their life work experience and the sorrows and triumphs of that journey. The openness and intimacy of this format for learning will make the more usual and traditional conference format hard to relate to in the future. Perhaps ANZSPM can adopt a similar round table format as an element in future meetings.

The discussion groups were interspersed with three plenaries, a memorial for deceased members, AGM and one proffered papers session, and the bountiful snack and meal breaks and social program. The conference dinner proved a highlight for the dancing, quite unexpected for the young band employed to provide music on a Thursday night to a group of 'death talkers'!

I hope to resume the conversation in two years' time in Canada.

Some resources and references for interest

Dougy Centre, National Centre for Grieving Children and Families Portland, USA. <http://www.dougy.org> (They have a large list of resources for purchase)

A research-based documentary, *Nurses grieve too: Insights into experiences with perinatal Loss* (Jonas-Simpson, 2011)

Colin Murray Parkes, Holly Prigerson *Bereavement: Studies of Grief in Adult Life* new edition 2010

REFLECTIONS

Why, why and why?

The three most important questions in the clinical practice of palliative medicine

The revolution in symptom control

CICELY SAUNDERS HAD seen the value of regular oral morphine in a small London home for the dying that she often visited. After qualifying, she obtained a research scholarship to study pain control in terminal illness and she went to St Joseph's Hospice, where she was allowed to put her ideas into practice. She was permitted only four patients to start with because of the fear that regular giving caused addiction! But, to the surprise and delight of the staff, these patients became pain-free and remained alert. So the practice of giving a strong opioid by mouth, regularly and in adequate doses became accepted at the hospice.

When Cicely Saunders left St Joseph's, she had carefully documented records of over 1,000 patients dying of cancer—quite a series. The first research project in what was to become palliative care.¹

The strong opioid used at St Christopher's at the beginning and listed in the hospice's symptom control leaflet is diamorphine, or heroin, because it was widely believed to be superior to morphine, giving better pain control with fewer side-effects. Cicely Saunders herself said 'Diamorphine does the greatest good to the greatest number'. But she also knew that this was only her impression and had never been researched. And so she invited Robert Twycross to join St Christopher's as a research fellow to conduct studies into many aspects of pain control, including a comparison between morphine and diamorphine given orally.

Because of the strongly held belief that diamorphine was the better drug, the only ethical way to proceed



Mary Baines worked for many years alongside Cicely Saunders at St Christopher's Hospice; she was one of the founders of the first UK palliative home care service.

was to do a pilot study first. Half the patients were given morphine and half diamorphine, and people like me were asked to guess which drug they were on. Not surprisingly, everyone who had good pain control with minimal side-effects we guessed to be on diamorphine. Those who were sick and drowsy we judged to be on morphine. In fact, we were right 50% of the time! The trial was then started with 700 patients entering over two years. On completion, when the data were analysed, they showed that there was no significant difference between them.² Cicely Saunders' impression was wrong. Of course, we too have impressions but, like her, we should be keen to have them tested out—even if we too are proved wrong.

If you had joined our ward round in the early years, you would have found that the most common word used was 'why': 'Why is this patient having this particular pain?'; 'Why has his breathlessness suddenly become much worse?'; and, relating to my own special interest, 'Why has this patient with proven intestinal obstruction stopped vomiting?'. This last question

was fascinating. We admitted many patients who had had an 'open and close' operation for intestinal obstruction and nothing could be done. We treated them simply, with a combination of analgesics, anti-emetics and antispasmodics with no nasogastric tube, and the vomiting either stopped or was reduced to once a day with no nausea. In addition, sometimes, after weeks, the bowels opened. Why was this? What was happening? It had never been described before.

Fortunately, when St Christopher's was designed, Cicely Saunders included a post-mortem room and we had a senior pathologist, Richard Carter, from the Royal Marsden Hospital, who came to perform limited symptom-directed post-mortems. Some of you here today attended them. I wonder if you, like me, remember that they mostly seemed to happen on a Saturday morning! The first 63 autopsies were written up in the first edition of the journal *Palliative Medicine*.³ Eighteen autopsies were in connection with our study of patients with malignant intestinal obstruction and, in each case, the obstruction was confirmed, with 14 patients showing it at multiple sites. This study, with 40 patients, was published in *The Lancet* in 1985.⁴ [It included the 18 autopsied patients and 22 on which it was not possible or not appropriate to conduct post-mortems.]

I hope that, if I joined your ward round next week, I would often hear the question 'why?'.

This is an excerpt from an article reflecting on the pioneering days of palliative care, when Dr Mary Baines worked with Dame Cicely Saunders at St Christopher's Hospice. The article is based on a speech given by Dr Baines in Lisbon in May 2011 at the 12th Congress of the European Association for Palliative Care. This excerpt is reproduced with permission from Baines M. From pioneer days to implementation: lessons to be learnt. *European Journal of Palliative Care* 2011; 18(5): 223-227. © Hayward Medical Communications.

For references see page 19.

Frank Brennan: Incoming president of ANZSPM

Frank Brennan is currently based at Calvary Health Care and St George Hospital. He is also a lawyer and has published extensively on the human rights dimension of pain management and palliative care.

Why did you make the switch from law to medicine?

It was a little more complicated. I completed my medical degree (UNSW) and worked as an intern and RMO in Sydney. I then worked in South Africa for two years—a year of paediatrics and a year of obstetrics and gynaecology. While there I commenced a correspondence law degree through the University of South Africa (UNISA). I returned to my home in Canberra and did the graduate law course at the Australian National University. Having gained a law degree I completed the requisite training in order to be admitted as a barrister and solicitor. Subsequently I worked as an associate to **Justice Mary Gaudron**, a judge of the High Court of Australia. This was an extraordinarily privilege and deeply matured my knowledge and appreciation of the law. It was a fascinating time to be present at the High Court as multiple areas of the law were being examined anew. The main medico-legal cases decided while I was there were *Rogers v Whitaker* (informed consent) and *Re Marion* (who should give permission for an intellectually disabled minor to be sterilised?). Without doubt the most important case to witness—in argument before the Court and then in the writing of the judgements—was *Mabo*.

After completing the associateship with the judge I re-entered medicine as a general practitioner at the Aboriginal Medical Service in Redfern. This also

was also a great privilege, working closely with an extraordinary group of Aboriginal health workers several of whom were members of the Stolen Generation. Redfern was known as 'The Mother House' as this was the place where the first Aboriginal medical service—and also the first Aboriginal legal services—in Australia were established in 1971.

Later, I re-entered hospital medicine, passed the physician exams and then completed my advance training in palliative medicine. My first year as a consultant was in Ireland.

Tell us about your interest in humanities and how you think it benefits doctors, especially those in training.

I have always had a love of literature. My interest was stirred in medical humanities when I worked as a palliative medicine consultant in Ireland. There I witnessed a culture with a deep and abiding love of language, literature music and art. Repeatedly the mysteries of death and dying were explored and expressed in these ways. Most inspiring was the work of **Dr Sinead Donnelly**, a palliative medicine consultant based in Limerick. She organised medical humanities conferences where doctors, poets, philosophers, musicians and artists would gather and relate stories and explore common mysteries such as suffering and mortality. These conferences were inspiring. In addition Sinead is a documentary filmmaker who has made a series of beautiful and fascinating documentaries around all aspects of our work.

To me humanities and palliative medicine are a natural fit. So much of our work with patients lies on a metaphysical, indeed spiritual, plane and it is to humanities we can turn to

gain insights and expressions of mystery. I think it should be incorporated into all aspects of training in palliative medicine. I find incorporating imagery, poetry and narrative very effective supplements in teaching for both undergraduate medical students and graduates, including trainees in palliative medicine.

Tell us about your work on pain relief as a human right.

This commenced with the smallest possible origin. In my final training year in palliative medicine I was looking around for a potential registrar project. One day I read a speech given by **Professor Michael Cousins**, a leading authority on pain medicine in Australia and internationally. In a major speech given in the USA he reflected on the inadequacies of pain management around the world and said: 'I put it to you that pain relief should be seen as a basic human right'. Immediately I looked at this statement and thought, here is a clinician using the language of the law—international human rights. Sympathetic, of course, to his passion I also thought, 'I wonder what a human rights lawyer would make of this statement?' That then became my final year project. My supervisor sent my project to Professor Cousins and we met. So began an extraordinarily rich journey of scholarship, writing and collaboration examining the human rights dimensions of, initially, pain management (with **Michael Cousins** and **Dan Carr**) and, later, palliative care (with **Liz Gwyther**, palliative medicine consultant in South Africa, and **Richard Harding**). The publications that have emerged from that collaboration have, in part, along with considerable advocacy work, given foundation to the Joint Declaration and Statement of Commitment on Pain Management and Palliative Care as Human Rights (2008) and The Montreal Declaration (2010) and statements of endorsement from senior human rights representatives of the United Nations. ■

EDUCATION

Churchill Fellow explores international palliative care volunteer models

Sue Salau is a leading voice for palliative care volunteerism throughout Australia. In 2010 she was awarded a Churchill Fellowship which allowed her to explore international palliative care volunteer models. Sue currently manages the Victorian Department of Health's Palliative Care Volunteer Strategy and is assisting Palliative Care Australia with the development of a national palliative care volunteer workforce strategy.

VOLUNTEERING HAS ALWAYS been fundamental to the palliative care movement and is vital to the future of palliative care, yet in my 17 years working in the Australian palliative care field, as a Clinical Nurse Consultant and Policy and Program Manager, I have found that palliative care volunteers are often under-utilised and their roles misunderstood. It is time this changed!

In 2010 I was awarded a Winston Churchill Fellowship which allowed me to explore international palliative care volunteer models in Singapore, England, Canada and the United States. From March to July 2011, I explored national and local palliative care volunteer standards and policies, recruitment strategies, training, roles and support mechanisms. I visited numerous palliative care services, oncology and end of life programs, peak palliative care bodies and palliative care research institutes.

My findings were encouraging. There is increasing international research in the palliative care volunteer area and palliative care services are implementing numerous strategies to strengthen their volunteer programs in the face of rising demand and other imposing factors. I was very impressed that in many areas of Canada volunteers are promoted as a 'discipline' in palliative care analogous to medicine, nursing and allied health.

Dame Cicely Saunders, the founder of the palliative care movement, saw volunteers as the lynchpin for responding to the emotional and social dimensions of many of the issues faced by patients and those close to them. She promoted volunteers as vital core members of interdisciplinary palliative care teams.

Now volunteers provide much of the respite, emotional and social supports to the terminally ill and their carers and assist with fundraising, governance of palliative care organisations and promotion of palliative care principles. Most importantly, volunteers bring normality into the lives of the terminally ill and their carers during a time that may otherwise be dominated by medical treatments. They are often the one constant for patients and families and as a result can get to know them much better than the doctors and nurses. Appropriately trained volunteers can take over some tasks from professional staff, reducing their stress or enabling the service to take on more clients.



Sue Salau (right), pictured with Professor Sheila Payne, Help the Hospices Chair in Hospice Studies and the Director of the International Observatory on End of Life Care at Lancaster University in the UK.

Both nationally and internationally the profile and required skill set of the palliative care volunteer workforce is now being shaped by changing demographics, patterns of disease, increasing demands for quality care and regulation, system-wide shortage of health care professionals and reforms to health care. To remain viable and responsive to patient and carer needs, palliative care volunteer programs need to keep abreast of these changes.

It became apparent through my travels that the palliative care volunteer model is moving away from the 'classic' service model of volunteer recruitment and utilisation that depends on staff identifying opportunities for using volunteers. It is moving towards one where the executive and key individuals in the organisation, state and national Manager of Volunteer Networks, volunteers and communities together assist in extending the vision of palliative care volunteer programs.

In Singapore HCA Hospice Care staff and volunteer educators are engaging with primary schools, secondary schools and universities through their Young Caregivers Program. This program aims to change the image of hospice in

EDUCATION

Singapore and bridge the gap between the old and the young. Since inception more than 48,000 students from 130 education institutions have participated in the program which provides both education in schools and a visit to the day hospice. This program also indirectly educates the parent through the children. Some parents then volunteer and when students are old enough many go onto volunteer in hospice activities.

In England I spent time at St. Christopher's, St. Joseph's Hospice, Marie Curie Cancer Care, St. Ann's Hospice and the International Observatory on End of Life Care. Hospice organisations are beginning to integrate the management of volunteer programs into their executive management structure following recommendations from recent research. Rather than a Coordinator of Volunteers endeavouring to fulfil the multiple roles of recruiter, trainer, coordinator and supervisor, they are developing mechanisms to share the load across the organisation. Trained volunteers are also increasingly used in the homes and in health promotion to educate communities on palliative care, advance care planning and the normalisation of death and loss.

Canada has developed palliative care volunteer national norms of practice and is currently developing a national palliative care volunteer induction training program. In Montreal I met with the Managers of Hope and Cope and Cedars CanSupport. Both programs provide specially-trained cancer survivor volunteers to support, inform, resource and guide patients through the cancer continuum within the hospital—oncology outpatient clinics, radiotherapy departments, and oncology and palliative care wards.

I was invited to add San Diego Hospice and the International Institute of Medicine to my schedule. Here the skills of the palliative care volunteer are highly valued and volunteers are involved in many aspects of service planning, development and delivery.

San Diego Hospice offers home support volunteers plus extra programs such as pet therapy, spiritual support volunteers, constant companions (shift volunteer sitters who watch delirious or agitated patients in the hospice units and cover 24/7 if required), notary volunteers (volunteers who certify signatures on forms associated with advance care planning), energy

therapists (e.g. Reiki and massage practitioners), 'made with memories' (where volunteers make dolls from the clothing of someone who has died) and promotional volunteers (volunteers, who have received speakers bureau training from the hospices marketing department, speak to local groups upon request). A Vet to Vet project will soon be rolled out as San Diego has a large navy population due to its port location. This program will offer veterans with palliative care trained volunteers who are also veterans.

Conclusion

Australia appears to be leading the way in its use of palliative care volunteers in the home and within aged care, however there is much we can learn from international experience.

My key recommendations to government and services were:

- There is a need to develop a nationwide approach to the fostering of palliative care volunteer best practice, standards, competency based training and research.
- The management and strategic development of the palliative care volunteer program should be integrated into the executive management structure of the organisation.
- Volunteer recruitment and use must reflect the cultural and social profile of the organisation's catchment.
- Volunteer skills should be well utilised and their roles extended.
- Strategies for shared volunteer training opportunities with other palliative care and volunteer organisations should be implemented.



Sue Salau (centre) with colleagues from HCA Hospice Singapore

Sue's full report can be viewed on the Winston Churchill Fellowship website <http://www.churchilltrust.com.au/fellows/detail/3458/>

LETTER FROM ABROAD

Palliative care development in Malaysia: 'Well, I guess I asked for it!'

By Richard Lim

It has been just under four years since I returned to Malaysia, having completed my training in Australia with the Sydney Institute of Palliative Medicine.

I WAS SENT to Australia by the Ministry of Health (MOH) of Malaysia to train in Palliative Medicine in 2006. At the time I was an internal medicine specialist but had been dabbling in palliative medicine since 1998.

In Malaysia the concept of palliative care began to take form in the early 1990s with several non-governmental organisations developing community services which were very much volunteer- and charity-based. In the mid-90s, palliative care services then began to develop within the MOH hospitals, and eventually in 1998 a directive was issued that all major MOH hospitals were to set up in-patient palliative care units. That was when

I took the opportunity to develop my first palliative care unit in the Alor Setar Hospital in the state of Kedah. I was a young resident in my second year, but already deeply inspired by the work that hospice care stood for. Hardly anybody in my hospital understood much about palliative care, so when the directive to start a palliative care unit came out, they were all lost for what to do. I actually heard the hospital administrators saying, "Maybe we can put a few beds up for destitute patients and if nobody is using it, the house officers could use it to double up as an extra on-call room."

I immediately volunteered to start up the unit with three beds, two nurses and a handful of volunteers. Not long after, the unit flourished and the bed numbers increased to six and I had five nurses working shift duties. My volunteer group grew to about 30 members, and soon the Kedah Hospice Association was formed.

It is one of the fondest memories of my career as I felt that I was really practising what I always felt I had

been called to do. Sitting down with the family members, listening to the patients' issues and providing that comfort and care was all I ever really wanted to do. I still believe that if that was all I ever did till the end of my career, I would still consider my life fulfilled and meaningful. Anyway, as it would turn out, that was not what fate had in store for me.

In 2001, I left Alor Setar to return to my home town of Kuala Lumpur to train in clinical oncology and haematology. I was a registrar in what is still the largest hospital in the country, Hospital Kuala Lumpur, which is a 2300-bedded monstrosity with 83 wards spanning an area of 150 acres.

As I started my position in the radiotherapy and oncology department, patients all seemed to have a great need for pain control, comfort and support. Many a time during my breaks while on call, I would walk through the hospital grounds thinking to myself, 'where can I build a palliative care unit? This hospital really needs one!' My head of department was very much in support of the idea but unfortunately, it appeared that every inch of this 150-acre hospital was completely utilised. Nevertheless, I still tried, and wandered through the hospital grounds every time I was on call, hoping to find a crack in the concrete maze.

One day while wandering back to the oncology department, I bumped into **Dr Mary Cardosa**, the pain specialist whose father



Dr Mary Cardosa and Dr Richard Lim (both at far right) and their team in Selayang.

LETTER FROM ABROAD

(the late **Dato' John Cardoso**) was a pioneer of the hospice movement in Malaysia. She asked me, 'What are you doing here?' and I said, 'I'm wandering around looking for a place to build a palliative care unit. God only knows this place needs one!' She immediately said, 'You won't find any place here, but I have always wanted to start something in Selayang... Why not transfer over and build one there?' Six months later, in December 2002, I was transferred to Hospital Selayang as a clinical specialist in internal medicine, but with the understanding that I was to develop a palliative care unit to serve the region.

With just one resident, eight beds and eight nurses, we started the first specialised palliative care unit in the Ministry of Health. The unit gradually grew to 12 beds with two residents and 12 nurses, after which I gradually became recognised as a dedicated palliative care physician.

Just as when I was in Alor Setar, I was very happy with just doing the work and really did not think of expanding the service. However, in 2004 the unit received a significant degree of recognition by the higher administration of the MOH and the opportunity came to take things a step further.

I was invited to present the case for palliative medicine to become a recognised medical sub-specialty in the MOH. This would establish a more secure career pathway for the field and hopefully develop more clinicians to become clinical leaders who would then develop palliative care further throughout the country.

The presentation was to be made before the Director General of Health as well as the Chief Secretary of the MOH and I was told to be precise: 'Ten minutes presentation, five minutes questions!' Ten minutes later, there was a deep silence for about five seconds. There were no

questions... And then: 'Thank you so much, we have been waiting for someone to take this up for such a long time.' Speechless, I was then asked by a senior director: 'You are sure you want this? Then we have a scholarship for you. Where do you want to go?'

Australia has always been a partner in the development of palliative care in Malaysia. **Dr Rosalie Shaw** has always been a mentor to me and she linked me to SIPM where I had a very fulfilling experience with palliative medicine in Sydney.

I hope that someday,
all Malaysians in need
of palliative care may
access it wherever
they may be.

In January 2007, I returned to Malaysia and resumed my position as the National Advisor for Palliative Medicine in the MOH. We immediately started our fellowship training program in palliative medicine with two trainees. The training structure is fairly similar to that in Australia with internal medicine as a base specialty.

Since then others have come to join the force, bringing the total of palliative medicine physicians in the government sector to eight, with two major medical schools being involved.

Efforts are now underway to train palliative medicine physicians from all 13 states of Malaysia. There is also a move to improve networking and co-operation between the government services and the non-governmental hospice organisations in order to expedite and enhance development of palliative care services nationwide.

The MOH has recently concluded a two-day National Palliative Care Technical Working Group Meeting to discuss the drafting of a National Palliative Care Strategy. As for education, two major medical schools are developing undergraduate and postgraduate curricula to provide better exposure for our younger generation of doctors. The MOH is also developing an advanced diploma curriculum for palliative care nursing.

I often feel that I am too young to be holding this position as the National Advisor for Palliative Care in the MOH, and honestly, I would rather just be that simple doctor from Alor Setar. But as I see my patients increase in numbers, I can only think of those to whom we have not yet reached out, and who cannot access palliative care. I hope that someday, all Malaysians in need of palliative care may access it wherever they may be.

It is a daunting task to bear the burden of driving the development of palliative care in the MOH and I really wish there was a 'Palliative Care Development for Dummies' book I could refer to. I am therefore truly grateful for the encouragement and advice often given by my mentors and friends from Australia, namely **Rosalie Shaw, Ghauri Aggarwal, Richard Chye, Jan Maree Davis** and **Prof. Norelle Lickiss**.

About two years ago at a conference, feeling really exhausted, I lamented to **Dr Rosalie Shaw** about how tired I felt. She responded with her usual comforting words of wisdom and finally said, 'Well, I guess you asked for it!'. I guess I did, and tired as I may be, I am happy doing it.

Dr. Richard Lim is a Consultant Palliative Medicine Physician at the Hospital Selayang, Ministry of Health Malaysia.

HUMANITIES

The 70th anniversary of the death of Lou Gehrig

By Frank Brennan

THIS IS A story of language and grace. Of language, lay and medical that had simple origins and a legacy that lasts to this day. Of language, in one of the greatest impromptu speeches ever given under the most stressful of circumstances. Of grace in body, perfection in skill and execution. And later, of grace in response to the disintegration of that body, to the loss of career and of life itself.

Lou Gehrig and Babe Ruth were the greatest baseball players of their time. Both played for the New York Yankees. Their different temperaments were reflected in the demeanour of their playing. Ruth was flamboyant, spectacular and impetuous. Gehrig was shy, methodical and reliable. Indeed, he was the model of reliability. Lou Gehrig played an extraordinary 2,130 consecutive games between 1925 and 1939, a record that endured for five decades. He was a virtuoso with the baseball bat and a brilliant first baseman.

It began with a stumble. A slowing between bases, an uncharacteristically dropped ball. In the 1938 season Gehrig's form waned. During spring training in 1939, he struggled to hit balls that normally he would have dispatched with ease and fell clumsily from a bench. Once the season commenced he struggled in early games. Sports journalists speculated. Some saw his form as a product of years of an exhaustive playing schedule. One journalist, James Kahn, sensed there was a problem that lay beyond the natural diminution of skills with age:

I think there is something wrong with him. Physically wrong, I mean. I don't know what it is, but I am satisfied that it

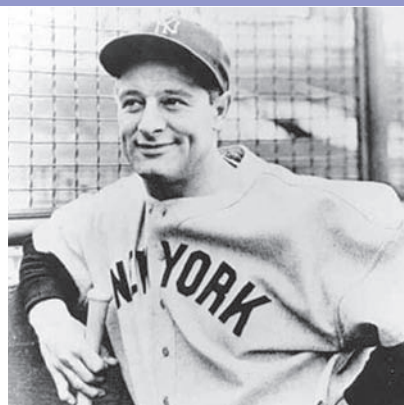
goes far beyond his ball-playing. I have seen ballplayers 'go' overnight, as Gehrig seems to have done. But they were simply washed up as ballplayers. It's something deeper than that in this case, though. I have watched him very closely and this is what I have seen: I have seen him time a ball perfectly, swing on it as hard as he can, meet it squarely — and drive a soft, looping fly over the infield. In other words, for some reason that I do not know, his old power isn't there... He is meeting the ball, time after time, and it isn't going anywhere.¹

This is a great piece of observation. Lou Gehrig's timing was perfect but his power had collapsed. It is a reminder to physicians about the importance of the first part of the examination of any patient—observing closely. After initially consulting doctors in New York without a clear diagnosis Gehrig spent a week at the Mayo Clinic in Minnesota. The diagnosis was made instantly by Dr Harold Habein who combined clinical knowledge with highly personal experience:

When Lou Gehrig entered my office I saw the shuffling gait, his overall expression, then I shook his hand, I knew. I had watched my mother go through the exact same thing. I excused myself from Lou and went straight to Dr Mayo's private office. 'Good God,' I told him, 'the boy's got ALS.'²

After speaking to him in detail, the Mayo Clinic gave Gehrig a letter explaining his diagnosis. It was his 36th birthday. Through his manager the letter was released to the press. It contained the following passage:

After a careful and complete examination, it was found that [Mr Gehrig] is suffering from amyotrophic lateral sclerosis. This type of illness involves the motor pathways and cells of the central nervous system and in lay terms is known as a form of chronic poliomyelitis (infantile paralysis).³



*'The Iron Horse', Lou Gehrig
1903–1941.*

In an attempt to explain the nature of ALS in lay language the letter unwittingly created confusion—that Lou Gehrig's condition was, like polio, an infectious disease. This confusion reached its apotheosis when a sports journalist, noting a recent slump in the form of several players in the New York Yankees, wrote an article speculating that Gehrig's disease was infectious and that his illness had been transmitted to his team mates.⁴ This confusion was only clarified when journalists interviewed doctors at the Mayo Clinic.

The speech

In June 1939 the New York Yankees announced Gehrig's retirement and proclaimed July 4 'Lou Gehrig Appreciation Day' at Yankee Stadium. A ceremony was held on the ground. In its coverage the following day the *New York Times* reported :

Perhaps as colorful and dramatic a pageant as ever was enacted on a baseball field [as] 61,808 fans thundered a hail and farewell.

Dignitaries extolled Gehrig. The Mayor of New York City,

Fiorello La Guardia called him 'the greatest prototype of the best to be found in sportsmanship and citizenship'.⁵ The team's manager, Joe McCarthy, who had been close to Gehrig for many years, concluded:

Lou, what else can I say except that it was a sad day in the life of everybody who knew you when you came into my hotel room that day in Detroit and told me you were quitting as a ballplayer because you felt yourself a hindrance to the team. My God, man, you were never that.⁶

After the presentations Gehrig addressed the crowd. It was a short speech but became known as one of the greatest speeches of sporting history. Indeed, in a book reproducing the greatest speeches of the 20th Century, it is included, perhaps, as much for its fame and context as its content. Gehrig said:

Fans, for the past two weeks you have been reading about the bad break I got. Yet today I consider myself the luckiest man on the face of the earth. I have been in ballparks for seventeen years and have never received anything but kindness and encouragement from you fans.

Look at these grand men. Which of you wouldn't consider it the highlight of his career just to associate with them for even one day? Sure, I'm lucky. Who wouldn't consider it an honor to have known Jacob Ruppert? Also, the builder of baseball's greatest empire, Ed Barrow? To have spent six years with that wonderful little fellow, Miller Huggins? Then to have spent the next nine years with that outstanding leader, that smart student of psychology, the best manager in baseball today, Joe McCarthy? Sure, I'm lucky.

When the New York Giants, a team you would give your right arm to beat, and vice versa, sends you a gift—that's something. When everybody down to the groundskeepers and those boys in white coats remember you with trophies—that's something. When you have a wonderful mother-in-law who takes sides with you in squabbles with her own daughter—that's something. When you have a father and a mother who work all their lives so that you can have an education and build your body—it's a blessing. When you have a wife who has been a tower of strength and shown more courage than you dreamed existed — that's the finest I know.

So I close in saying that I might have had a bad break, but I have an awful lot to live for. Thank you.

Correspondence between doctor and patient

One of the doctors Lou Gehrig consulted at the Mayo Clinic was Dr Patrick O'Leary. From the time of his diagnosis Gehrig embarked on a long correspondence with

O'Leary. It is an extraordinary record. There are two fascinating aspects to this correspondence. The first is the meticulous documentation by a patient of his symptoms with ALS over a two-year period. It clearly sets out the deterioration of his peripheral strength, fibrillations, ability to function with basic tasks, mobility, speech, swallowing and breathing. When he could no longer write legibly he dictated letters for as long as he was able to speak intelligibly.

The second aspect was hope. A critical aspect of the diagnosis and management of any serious life-limiting condition was, and remains, how much to inform the patient of their prognosis and the likely trajectory of his or her symptoms.

In Gehrig's case a dance ensued between patient and doctor. The letters reveal a deep trust that Gehrig placed in O'Leary. That trust was returned by wise counsel and comfort. The unspoken concern of O'Leary is that the unadorned truth about the catastrophic nature of the disease and its inexorability could be harmful to Gehrig. Repeatedly Gehrig anticipates that concern and writes to his doctor 'I am not crying' and 'Don't think that I am depressed or pessimistic'. Repeatedly also Gehrig linked that reassurance with a plea to tell the truth: 'I feel you can appreciate how I despise the dark, but also despise equally as much false illusions.' For O'Leary it was a thin and difficult line to walk. At one stage in December 1939 he wrote a letter to Gehrig that says, in part, 'courage and persistence in treatment invariably result in an arrest of the process such as you have'.⁸

This interaction is made more complicated by an external influence. From diagnosis, Lou's wife, Eleanor, explicitly requested that the doctors not inform Lou that ALS was ultimately fatal and requested that his spirits be buoyed by 'hopeful' entreaties.

In March 1940 Lou wrote to Dr O'Leary requesting his 'honest opinion'. Soon after Eleanor followed that letter with one of her own to the doctor:

It must be very difficult for you to answer his last letter to you, and I feel we must all lie like mad. I want him to keep a thread of hope; there is no point in adding mental torture to the horrible experience he is now going through.⁹

Hope manifested in various treatments he undertook—histamine injections (Dr Bayard Horton, Mayo Clinic) and high dose Vitamin E (Dr Israel Wechsler, New York). Even minute reversals of power loss were documented and, in one instance at least, was seen by a clinician as indicating that his disease was 'definitely arrested and somewhat improved'. Despite these messages Gehrig was increasingly conscious that his losses were not only irreversible but compounding. In January 1941 he wrote to O'Leary:

As for myself it is getting a little more difficult each day and it will be hard to say how much longer I can carry on... I don't mean to be pessimistic but one cannot help but wonder how much further this thing can go... I intend to hold on as long as possible and then if the inevitable comes, I will accept it philosophically and hope for the best. That's all we can do.¹¹

By the spring of 1941 an interesting shift in the tone and content of Gehrig's letters to O'Leary occurred. He no longer discussed his condition or asked O'Leary for his opinion. The principal concern in the letters is the health problems of his family and friends. An interchange with a visitor at this time is revelatory:

I'll never forget what he said as we were going. He said, 'Goodbye, boys, nice of you to come here. The doc says that I'm going to be all right. He said I have to go downhill and hit rock bottom before I come back.' He knew, he knew.¹²

Continued on page 17 ►

HUMANITIES

A letter to Aafje

Dear Aafje

SAD TO HEAR that your closest friend, your body, who has served you well throughout all those years, has given up on you. I am sure you would have liked to linger a bit more just to witness how the lives of your children and grandchildren would further evolve. But your body did what it managed to do even in *blessuretijd* (injury time): adding years to your life among family and friends. We must thank you for 'being around' that long. A gift in itself. A friend of mine always spoke of his body as of a donkey, dedicated and, on the whole pretty reliable, meek to some extent, but getting more stubborn as it aged, causing one the unavoidable worries, pains and aches. It served you well throughout your 95 years.

It is a bit awkward to now address you 'in person' as you can no longer respond to what is written/said 'in memory' of you. But that doesn't matter because bonds between people remain even if death does us part in a physical sense. You know that and we share that knowledge. However, by letting go of the realm we live in, you handed your take on what is precious in life and what must be preserved, on what feeds our wellbeing and happiness, to the next generation of family and friends, especially to your two daughters and your grandchildren. They were and are close to your heart. From now on it is their task to nurture your heritage. Needless to say they will.

We open that treasure chest to explore what has kept you going all those years and what, in turn, we need to store away to our own benefit. Life wasn't a bowl of cherries. Born in the Low Countries, you headed for Australia hoping for a better life, or at least a life with more prospects than Holland had to offer.



Aafje Heineke and Herman Meijburg

But emigrating to another country doesn't imply that life automatically takes a turn to the better. Life in Australia has not been a smooth ride and unexpected circumstances put you in the seat of control whether you wanted to or not. When your husband died, you had to make a living for your children single handed in a foreign country. And you managed to do just that. There was this temptation to retreat to the old country you once called home, but you knew instinctively that that road back was closed. Your future and that of your children was in Australia and, on their behalf, you never gave up on that idea.

To proceed quietly with a definite sense of persistence is an art, maybe a typical Dutch personality trait too. It takes courage to, in times of adversity, stay put and to let the world know you intend to make the best of it right there where you are. You truly became the family pioneer, facing all the ups and downs that come with it. Thus paving the way for your children to live and to thrive in a foreign country. A priority set and a job well done, Aafje.

You held some strong opinions in your life. A bit 'thorny' for others at times. Nevertheless, they now form a great reminder of who are. You wanted to be in control of your life to the very end. It was born out of necessity, simply because you had to. Yes, in that respect you are a Dutch thorough bred. If you could have been in control of your own birth you would have seized that opportunity as well. A strong personal sense of what was the 'right' thing to do, and of what would otherwise 'complicated matters'.

Taking that 'high ground' comes with a price: this feeling of being alone with the views you stand for and hold important. Like Frank Sinatra, you did it your way. You applied this rule of thumb to your own life, at the same time it is a sign of character to respect the choices family members made, whether or not they met your own hopes/expectations. By carrying that burden you helped others to take responsibility for their own choices in life; worried, yet demonstrating what it takes *to be a mother* to the ones you love so dearly.

On another note, you identified your religious beliefs with those of the Remonstrants, bringing the mindset of that religious model, that more rational kind of spirituality, to Australia. That religious heritage set you apart in the Netherlands, let alone Australia. Their heritage is rooted in the struggle for free will, personal responsibility and a very present inner spirituality, abhorring any kind of intellectual dominance.

It started as an early post-Reformation development in the Netherlands and carries a long history of proud and eminent thinkers. In comparison to other denominations the Remonstrants have always been a comparatively small group, but they have left a distinguished and much respected mark on Dutch society to this very day. Remonstrants 'stand tall' and you carried that 'Rem'-mark with you when you emigrated to Australia.

In line with the above it is no surprise we had an open 'Dutch' discussion

how we expected to die and to what extent we would be able to control that process. We concluded that much would be about who would be there with us when times comes. We also agreed that, ideally, the best way to die would be to die in your sleep. But how many of us 'die in their sleep?' Statistics tell us 'not many'. Guess what? You just did what you hoped what would happen to you.

I didn't want these ponderings be a casual, superficial story about *pepernoten* (pepper nuts) or *stroopwafels* (syrup waffles), nor a story about setbacks, worries and disappointments, because at the end we all realise that life is not without its challenges, not without a give and take. There is a balance to be appreciated. Also a life lived is a life lived with family and friends, with the people we love and hold close to our heart. When Maori are asked 'What is the most important thing in the world?', the answer is '*He tangata! He tangata! He tangata!*' ('It

is people! It is people! It is people!') At the end, the story of your life is a story about people, about yourself, your husband, about *de meisjes* (the girls), your grandchildren, family and relatives, friends, both in the old country and here in Australia. To find yourself embedded in the hearts of many is a blessing and well worth acknowledging today. Your life is not over yet, but will continue to be celebrated as long as 'people' think of you or mention your name.

I thank you for this opportunity, *vriend* (friend), to pay you *our* respects.

With love, Herman Meijburg

Herman Meijburg is a grief counsellor and a death educator. He studied theology, pastoral counselling and applied philosophy and was the Director of the Bioethics Department of the Dutch Hospital Association for many years. He currently runs the Centre for Loss and Healing in New Zealand.

◀ Continued from page 15

Lou Gehrig

Perhaps the clearest description of the inexorable effect of ALS came from the recollection of Eleanor Gehrig:

There was no hope in it anywhere along the line, just downhill going, every day a little more downhill... [He] just died away by inches, every day a little bit more... Every once in a while, when a new symptom came on, when another part of his body fell still on him and become dead, he'd break down somewhat and shake his head and say he didn't think he'd come out of this thing so well... I would tell him I was sure he would... and after a while he'd be back to the way he was, that quiet way of his, that wonderful quiet way of his.¹³

By mid-May he became progressively more breathless. As his wife recalled, he was 'like a great clock winding down'.

On the morning of June 2, 1941 he became unconscious. He died later that night in his home. He was 37 years old.

Mayor La Guardia ordered all flags in the city flown at half-mast. Thousands attended his memorial service. The officiating Minister at the funeral announced there would be no eulogy as, 'We need none, because you all knew him'.¹⁴

The shining theme of the life, illness and death of Lou Gehrig was grace. He displayed remarkable grace in all circumstances—from the height of sporting success and fame to the depth of his private grief and loss. The brilliance of his gifts and the tragedy of his passing have forever entered American lore. And fittingly so.

Dr Frank Brennan is a palliative care physician in Sydney.

References

1. Kahn J. *The New York Sun*, 1938. Quotes about Lou Gehrig -lougehrig.com.
2. Bak R. *Lou Gehrig: An American Classic*. Dallas TX: Taylor Publishing Co. 1995.
3. Letter signed by Dr H. Halbein, June 19, 1939. In Eig J. *The Life and Death of Lou Gehrig*. Simon and Schuster Paperbacks. 2006, pp. 307-308.
4. Powers J. Has Polio Hit the Yankees? *Sunday News*, August 18, 1940. For an earlier press article where the journalist researched the true nature of ALS see: "Gehrig Case is Expected to Spur Research into Baffling Malady." *New York Times*, June 29, 1939.
5. "Gehrig Day Epic Event", *New York Post*, July 5 1939.
6. Eig, op. cit., p. 15.
7. Gehrig – O'Leary correspondence. November 1, 1939.
8. Dr P. O'Leary. Gehrig-O'Leary correspondence. December 8, 1939.
9. Letter from Eleanor Gehrig to Dr P. O'Leary, April 9 1940. Quoted in Eig, op.cit., pp. 344-345.
10. Case "LG" in: Weschler I. The Treatment of Amyotrophic Lateral Sclerosis with Vitamin E (Tocopherols) *American Journal of Medical Science* 1940; 200(6): 765-778.
11. Gehrig-O'Leary correspondence, January 1941. Eig, op. cit., p. 350.
12. Tommy Heinrich. In: Eig, op.cit., p. 355.
13. "Mrs Lou Gehrig Recalls the 'Iron Man's' Great Fight for His Life", *St Louis Daily-Globe Democrat*, September 20, 1941.
14. "Funeral Service for Gehrig is Held." *New York Times*, June 5, 1941.

POSITIONS VACANT

Otago Community Hospice

Medical Vacancies



The Otago Community Hospice is located in Dunedin, a vibrant university town in the South Island of New Zealand. Dunedin is only three hours away from Central Otago and Queenstown and has on its doorstep adventure tourism, winter sports, winemaking regions, tramping and much more.

The Otago Community Hospice provides community-focused specialist palliative care and is based in Dunedin with an outreach programme serving North, South and Central Otago. A 12-bed Inpatient unit is located in Dunedin. The service is fully committed to an interdisciplinary approach. There is a strong relationship with Otago Medical School, Dunedin Public Hospital, including the Hospital Palliative Care Team and other Community Services.

Medical Leader

The Otago Community Hospice has a great opportunity for an energetic Palliative Medicine Specialist looking to take on a leadership role. The Medical Leader is one of three Clinical Leaders at the Otago Community Hospice comprising the Clinical Governance Team, which is responsible for the clinical management of patients and families on the Hospice Programme throughout Otago.

The position offers extensive teaching opportunities at an undergraduate level and in teaching and mentoring at a postgraduate level. Involvement in research is actively encouraged.

It is essential that applicants have excellent communication skills, a continuous improvement focus and total commitment to collaborative teamwork.

Palliative Medicine Registrar

The Otago Community Hospice has established a full time registrar position and is looking for medical practitioners interested in palliative medicine for six- to twelve-month posts.

The position is suitable for advanced training in Palliative Medicine with the RACP Chapter of Palliative Medicine. The position would also suit General Practitioners, Rural Doctors and other practitioners that are interested in learning more about specialist palliative care. We would seriously consider a job-sharing scenario.

The Registrar would work across the Hospice services with a focus on the inpatient unit. They would be responsible, medically, for the day-to-day management of patients and be supervised by the Medical Leader.

It is essential that applicants have excellent communication skills, a continuous improvement focus and total commitment to collaborative teamwork.

We are fully committed to providing ongoing professional development opportunities for all staff and offer excellent working conditions.

For further information about either of these roles please call:

Ginny Green, CEO on 00 64 3 473 6005
or email ginny.green@otagohospice.co.nz. All enquiries will be treated in the strictest of confidence.

ANZSPM1221

POSITIONS VACANT

Calvary Health Care Bethlehem, Melbourne

Palliative Medicine Consultant (MD2)



Calvary Health Care Bethlehem (CHBC) is a 70-bed specialist health care facility providing a range of inpatient and ambulatory services for palliative care and progressive neurological conditions.

CHCB is recognised as a provider of specialist palliative care and a state-wide specialist in progressive neurology, in particular Motor Neurone Disease, Huntington's Disease and advanced Multiple Sclerosis. In addition, CHCB is accredited by RACP as a training facility and with The University of Notre Dame provides teaching for final year medical students.

The successful applicant will be joining a growing and dynamic team providing specialist palliative medicine support as part of the interdisciplinary team across a range of settings – inpatient, community, outpatient clinics and consultancy outreach. This role will assist with strategic development of the palliative service including expansion of consultancy services and developing the research capacity of the service. In addition, the successful applicant will have/be:

- Medical Practitioner, with appropriate post-graduate Palliative Medicine qualifications, preferably Royal Australasian College of Physicians (RACP) or Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM) and eligible for registration as a medical specialist with AHPRA

- Skills and commitment to professional development
- Excellent communication and interpersonal skills
- Professional work ethic

Hours negotiable if preference is for part-time work.

Enquiries:

Ms Julie Gray, Executive Assistant
Telephone (03) 9595 3290

Applications:

Please forward to
julieg@bethlehem.org.au or
Calvary Health Care Bethlehem,
476 Kooyong Road, Caulfield
VIC 3162, marked attention
Ms Julie Gray.

The successful candidate will be required to disclose any pre-existing injury or disease which may be adversely affected by the performance of the inherent requirements of the position. The successful candidate for any position involving direct patient care will be required to participate in a police record check prior to confirmation of appointment.

Calvary Health Care Bethlehem is a Service of the Sisters of the Little Company of Mary, with values of hospitality, healing, stewardship and respect.

ABN 81 105 303 704
www.bethlehem.org.au

ANZSPM1214

◀ Continued from page 3

New Zealand Branch Chair's report

October saw the signing of the Memorandum of Understanding (more on this elsewhere in this newsletter) and **Sinead Donnelly** began work on obtaining an official translation of our Society name into Maori. This is well underway and we expect to finalise early in the new year.

In **November Amanda Landers** attended the R&C workshop in Wellington as the EC delegate. Two other EC members also attended that workshop, Carol McAllum as PCC rep, and I represented the northern region. So all in all ANZSPM (Aotearoa) was well represented that day.

We wrote to a number of organisations to introduce our society and make connections, including HNZ, PHARMAC, MoH, PCAG, HWNZ, Hospital Palliative Care New Zealand and Palliative Care Nurses New Zealand.

It has been a busy year for our branch and as chronicled here we have been active in addressing member concerns that we find an effective voice within the political landscape in New Zealand. This activity will continue in the coming year. ■

References for 'Why, why and why?' article, p.8

1. Du Boulay S, Rankin M. *Cicely Saunders, the Founder of the Modern Hospice Movement*, updated edition. London: SPCK, 2007: 49.
2. Twycross RG. Choice of strong analgesic in terminal cancer: diamorphine or morphine? *Pain* 1977; 3: 93–104.
3. Carter RL. The role of limited, symptom-directed autopsies in terminal malignant disease. *Palliat Med* 1987; 1: 31–36.
4. Baines M, Oliver DJ, Carter RL. Medical management of intestinal obstruction in patients with advanced malignant disease. A clinical and pathological study. *Lancet* 1985; 2: 990–993.



CONFERENCES & EVENTS

2-5 February 2012 Bengaluru, India
ISSPCON 2012: 27th Annual National Conference of the Indian Society for the Study of Pain
www.isspcon2012.com/

7-9 March 2012 Singapore
APREC 2012: Asia Pacific Research Ethics Conference 'Bridging Cultures, Enhancing Research'
www.aprec-mhg.com.sg/

21-22 March 2012 Sydney, NSW
2nd Whole Person Care National Symposium 2012
 Contact: wholepersoncare@iceaustralia.com

22-23 March 2012 Geelong, Vic
Continuing Conversations: Updating Professional Practice in Palliative Care ★ Registrations now open
 Email: heatherca@barwonhealth.org.au or phone 03 5279 2800

6-9 May 2012 Brisbane, Qld
RACP Future Directions in Health Congress 2012
www.racpcongress2012.com.au/

31 May - 2 June 2012 Chicago, USA
International Society of Advance Care Planning & End of Life Care Conference
www.racpcongress2012.com.au/

7-9 June 2012 Trondheim, Norway
7th World Research Congress of the European Association for Palliative Care

9-15 September 2012 Sunshine Coast, Qld
Australia & Asia Pacific Clinical Oncology Research Development (ACORD) Workshop 2012
www.acordworkshop.org.au

26-28 September 2012 Canberra, ACT
Ageing and Spirituality - 6th National Conference of the Centre for Ageing and Pastoral Care Studies
www.centreforageing.org.au/

9-12 October 2012 Montreal, Canada
19th International Congress on Palliative Care
www.pal2012.com

31 October - 2 November 2012 Dubbo, NSW
Reaching Out: 2012 NSW State Palliative Care Conference
<http://palliativecarensw.org.au/site/events/event/2012-nsw-state-palliative-care-conference/>



Editor's Note: The author of the article *Bring on the Angels: H.L. Mencken, death and palliative care* that featured in the August newsletter was **Dr Frank Brennan**. We apologise for the omission.

◀ Continued from page 5

Rapid pharmacovigilance

strategies and reduce the burden of harm in the management of end-of-life symptoms. The Palliative Care Clinical Studies Collaborative (PaCCSC) is coordinating a rapid reporting study involving 22 sites from five countries in the Asia Pacific region.

The aims of the study are:

- to prospectively collect information on the therapeutic benefit of medications commonly used in palliative care
- to prospectively collect information on the toxicity (drug/host) of medications commonly used in palliative care
- to prospectively collect information on any significant drug/drug interactions of medications commonly used in palliative care.

Quarterly audits will be conducted on four medications per year. A committee will define clinical benefit, expected toxicity data fields, timeframes for measuring these and ideal tools. Participating units collect a small number of data fields on every patient started on each medication in the three month period. Data entry through the CareSearch website (www.caresearch.com.au) provides rapid, real-time data collation so findings can be published regularly of the data. Findings from each audit will be published as a short piece in the Journal of Palliative Medicine.

These audits will allow the true net clinical benefit (therapeutic effect and toxicity) to be adequately evaluated in the patient population currently under the care of palliative care services. The audits have commenced in a small number of units but will grow in the years ahead as other sites become interested.

Further information is available through Professor David Currow (david.currow@flinders.edu.au) or the PaCCSC pages on the CareSearch website.