



Contents

| | |
|--|----|
| ANZSPM Position Statement on Quality End-of-Life Care – Part 1 | 1 |
| President's report | 2 |
| Editor's note | 2 |
| ANZSPM Aotearoa Branch Chair's report | 3 |
| New ANZSPM Council Member: David Holden | 3 |
| Essential Pain Management: Experiences in Fiji and Tuvalu 2013 | 4 |
| Palliative care training in Samoa: 7-15 April 2013 | 6 |
| New Zealand Pacific Palliative Care Network | 8 |
| Journal Club | 12 |
| Advertisements | 17 |
| Conferences & Events | 20 |

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ANZSPM Position Statement on Quality End-of-Life Care – Part 1

Essential elements for quality, safety and appropriate clinical care at the end of life.

Preamble

This position statement is the first in a series of two documents, designed to guide and encourage clinicians, health planners and agencies that set and monitor standards for safety and quality pertaining to the provision of Quality End-of-Life Care (EoL Care) for patients, families, loved ones and carers. These statements will help guide clinicians who are managing issues associated with their patients' last 6–12 months of life. Some of the elements outlined would be applicable even earlier in a patient's journey, at diagnosis of a life-limiting illness.

Part 1 specifically outlines evidence-based guidance for Quality EoL Care assessment and planning. Emphasis must be placed on the individual and their specific needs, to ensure that the process enhances patient preferences and involves family, loved ones and carer engagement in the health planning and care support processes.

Part 2 will be developed over the next few months and focus on evidence-based implementation strategies aimed at delivering quality EoL Care in the setting of patient choice, where possible.

Background

The Australian and New Zealand Society of Palliative Medicine Incorporated (ANZSPM) is a specialty medical society that facilitates professional development and support

for its members. ANZSPM promotes the discipline and practice of Palliative Medicine in order to improve the quality of care of patients with palliative diagnoses, and support their families.

ANZSPM members are medical practitioners. They include Palliative Medicine Specialists, doctors training in the Palliative Medicine discipline, General Practitioners (GPs) and doctors who are specialists in other disciplines such as oncology.

Introduction

Modern medicine has a long history aimed at 'curing' disease and 'prolonging life'. Clinicians, scientists and public health officials have been extraordinarily successful at prolonging life in many countries with advanced health systems in place; achieving major improvements in longevity for many populations. Notable exceptions have of course been in indigenous, lower socio-economic and rural and remote sub-populations. The remarkable achievements of increased longevity have also been accompanied by the creation of new patient sub-populations that are medically more complex and burdened with chronic disease and/or 'advanced frailty'. Managing this EoL sub-population under the 'traditional models-of-care' with a focus solely on 'curative' or 'life-prolonging' intent, rather than having a concurrent goal of 'enhancing quality

ANZSPM

President's report



By Mark Boughey

WELCOME TO THE first ANZSPM Newsletter for 2014. If I were to choose a word that best describes

the gathering pace of activity within ANZSPM, the elected Council and you, the membership, it would be 'momentum'. We are increasingly engaging with our members, as well as various organisations that seek our input regarding issues pertaining to end-of-life care, palliative care and palliative medicine.

In recognition of our growing work needs, when Council met for its first face-to-face meeting of the year on 14 February, not only did we readily move to augment our Executive Officer **Marita Linkson's** working hours from 25 to 30 hours a week, we also approved the appointment of a personal assistant for the first time. **Andrea McDermott** joins us for five hours a

week to assist with general ANZSPM business, plus another five hours per week to support the national Specialist Palliative Care and Advance Care Planning Advisory Services project.

At the meeting, we also welcomed **Amy Birtwistle** (NSW) and **David Holden** (SA) as new co-opted members to the table. Amy takes over the role of trainee representative from **Vicki Tai**. Although it is early in the year, we need to think ahead to our Annual General Meeting at the ANZSPM Conference in September, during which a number of Council positions will become available (including president-elect). We invite our members to express their interest in joining Council.

The new Advisory Services project may seem little more than a promise and a whisper. However, I can assure you that the emerging project team, Marita and I have been working hard behind the scenes. Being part of a \$15 million project has brought with it significant governance and contractual requirements, both with Austin Health (the project lead) and in establishing an ANZSPM project team. Those of you who understand organisational risk will recognise the financial risks that a small organisation such as ANZSPM can face.

Our primary commitment is to the GP Education and Resources arm of the project, which will involve the development and delivery of education packages to GPs. We are also contributing to the Project Evaluation component, which includes coordinating and participating in the broader project evaluation. **Liz Reymond** is the ANZSPM Project Director and **Michael Chapman** the liaison between Council and the project.

In addition, each component of the larger project is establishing advisory groups. We have been heartened by our members' willingness to participate in these groups, both as representatives of ANZSPM and of the RACP Chapter of Palliative Medicine. To date, we have engaged the following ANZSPM representatives: **David Healey** on the ANZSPM GP Education and Resources Advisory Group, **Sue Rainsford** on the ANZSPM GP Education and Resources Project team, **Sarah Pickstock** on the PCA Advisory Services Set Up Project Board and **Christine Sanderson** on the CareSearch Guideline and Technological Innovation Advisory Group.

Our thanks go to **Janet Hardy** for her excellent work representing ANZSPM

Continued on page 16 ▶

Editor's note



THIS ISSUE OF the Newsletter features the newly released ANZSPM Position Statement on Quality End-of-Life Care (Part 1),

which provides evidence-based guidance on assessment and planning.

The authors highlight the need to shift community perception of a referral to specialist palliative care from an 'admission of defeat' to a way of ensuring that the 'best care possible' is delivered at the end of life. They clarify the concepts of palliative care, end-of-life care

and specialist palliative care, and discuss the four essential processes (or principles) and five domains (or clinical indicators) that should underpin all quality end-of-life care.

Following on from **Bruce Foggo's** article 'Outreach to the Cook Islands', published last July, we once again focus on the Pacific and the work being done to promote palliative care in our region. Through a series of reports by **Linda Huggins, Sue Marsden, Liese Groot-Alberts** and **Sara Rishworth**, we may begin to appreciate the challenges faced by our colleagues working in Fiji, Tuvalu, Samoa and other Pacific nations.

In Journal Club, we discuss two recently published papers on topics

of great clinical relevance to palliative medicine – a retrospective study comparing renal replacement therapy and conservative management in end-stage renal failure, and a systematic review on death rattle. As usual, we complement each study summary with an invited commentary from an expert in the field. Join us to find out how the latest research may (or may not) influence your practice.

Finally, I would like to wish our readers a belated Happy New Year and hope that 2014 is shaping up to be a fun and fulfilling year for everyone. See you all at the upcoming ANZSPM conference on the Gold Coast!

ANZSPM Aotearoa Branch Chair's report



By **Sinead
Donnelly**

**So Much Depends upon
a Red Wheel Barrow**
–William Carlos Williams (1923)

So much depends
Upon

A red wheel
Barrow

Glazed with rain
Water

Beside the white
Chickens.

An American writer and physician, Williams is credited with saying 'No ideas but in things'. Williams had the view that poetry shouldn't philosophise, it should present. It

should show, not tell. His poem about a red wheelbarrow is the best-known example of Williams's technique. Making the ordinary remarkable is the stuff of poetry. Each new line, while following on from the last, gives a little jolt, lending a strange intensity to the poet's perceptions. It's as if the deliberate slowness and line break forces the reader to scrutinise everything with intensity. Williams makes the reader pause for everything in the poem, pause worthwhile. W.C. Williams' poetry reveals a physician of rare humanity and self-knowledge.

As my second year as Chair of ANZSPM Aotearoa unfolds, I take the liberty of adding poetry to my report. Take it as you will. From my perspective, the poet's precise observation enunciates the quality of observation, fundamental to the practice of medicine. For that reason I have included Dr Williams' work above. I trust the editor will not remove it! *[Editor: Most assuredly not. I love it!]*

ANZSPM Aotearoa prepares for its annual meeting on 14–15 June in Wellington. We are getting ready for a turnout of at least 50 members. We hope for an increased attendance by advanced trainees, providing

them with a dedicated platform to present their research projects. To acknowledge the great work done in paediatric palliative medicine led by **Ross Drake and Emily Chang**, we will invite them to lead our discussion on transition from paediatric to adolescent and adult palliative care. The debate this year takes a 360-degree look at advance care plans in the health care system. We will have updates in respiratory/palliative medicine and medical oncology. We will also hear reports from international conferences, as well as personal experiences of working and teaching in India. **Sue Marsden** will close the conference by reflecting on her wide experience as a palliative medicine physician.

We also welcome ANZSPM president **Mark Boughey** to Wellington in June. The second day of our annual meeting will include a discussion on the palliative medicine undergraduate curriculum, with input from Mark on his experience in Melbourne.

At our last executive teleconference, with bioethicist **John Kleinsman** as guest participant, we discussed the impact of euthanasia legalisation on medicine as a profession and the doctor–patient relationship.

Continued on page 16 ▶

David Holden

New ANZSPM Council Member



DAVID WAS BORN, raised and completed his medical studies in Adelaide. He worked in emergency medicine and in a private intensive care unit, whilst complet-

ing a master's degree in Christian studies. General practice training followed. David continues a relationship

with general practice, working as a college examiner and as a casual medical educator for one of Adelaide's regional training providers.

David is currently completing an oncology term at the Queen Elizabeth Hospital as a palliative medicine trainee and anticipates finishing his training in August 2015. He is also undertaking a Graduate Certificate in Clinical Education, which stems from his interest in clinical education and medical ethics. He is actively involved in resident/intern teaching. In addition, David is intrigued by how the relationship between palliative

medicine and general practice will be strengthened in years to come.

Outside of medicine, he answers to a wife, two teenage children, a dog, budgie, multiple fish, two turtles and four chickens. He also hopes to have completed his first Ironman triathlon by the time of publication. Despite how his biography reads, he is aware of work-life balance and rumour has it he has been seen to stop and smell the roses.

David is a co-opted trainee member of ANZSPM Council and the End-of-Life Working Group and is appreciating the opportunity to observe and participate within the wider palliative care community.

PACIFIC FOCUS

Essential Pain Management: Experiences in Fiji and Tuvalu 2013

By **Linda Huggins**
Palliative medicine specialist
Counties Manukau District
Health Board

PAIN IS AN unrecognised and inadequately treated problem. Like many developing regions, Fiji and Tuvalu have ongoing problems with staff shortages, an unreliable supply of drugs, limited educational opportunities and cultural differences, all of which can make pain management challenging.

Essential Pain Management workshops

Essential Pain Management (EPM) workshops are being used widely in the Pacific to help address these issues. These have been developed to improve pain knowledge, provide a simple framework for managing pain and address pain management barriers. The workshops were created by **Roger Goucke** and **Wayne Morriss** and have been conducted since April 2010. As of September 2013, EPM workshops have been held in 30 countries worldwide.

The management framework used during these workshops is RAT,

which stands for Recognise, Assess and Treat. This has been used very successfully to discuss common – as well as more challenging – pain management scenarios.

A team of pain management specialists from New Zealand travelled to Fiji and Tuvalu in October 2013 to deliver a series of EPM workshops alongside local instructors. The team consisted of **Linda Huggins, Pam Eccles, Apaitia Goneyali** and **Shaku Prasad**. The trip was funded by AusAID through the Pacific Island Project and the Royal Australasian College of Surgeons. Over the course of ten days, four EPM workshops were held and 69 people trained. The workshops were organised and run primarily using local instructors, which was possible because of the previous training that had been done in Fiji. Three EPM instructor workshops were also held and 24 people were trained to become local instructors.

Outcomes from the visits

The course structure and teaching materials worked well and the RAT approach provided a simple framework to manage a variety

of pain problems. A number of participants commented on the clinical value of the teaching. Course participants contributed enthusiastically to discussions and came up with a number of ways of reducing pain management barriers.

An important part of EPM is early handover of teaching to local instructors and this seems to be happening in Fiji. The lead local instructors had prepared well for the visit, such as organising a teaching venue, printing materials, etc. After discussion in Lautoka, it appears that as a result of EPM teaching, the administration of placebo ('American pethidine') is no longer common practice.

One of the most passionate local instructors in Lautoka has now been promoted to Matron for Administration. With increasing numbers of local instructors, she now has the confidence and authority to run more workshops locally and organise development of policies, guidelines and audit.

In Fiji, oral morphine (including slow release preparation) seems to be more widely available. Morphine is now frequently used in preference to intramuscular pethidine and



regular paracetamol is also charted and administered routinely in the post-operative setting. There is commitment from Fiji National University to introduce EPM to their medical students next year and the Matron for In-service Training in Suva attended all three workshops.

In Tuvalu, participants interacted well with the tutors and with each other. They found the RAT model useful, and seemed eager to develop ways of improving healthcare for their community. They have already identified several barriers to the provision of healthcare and are working on ways of overcoming these. By the time we left the island, the local instructors had already organised the next EPM course so that nurses from the outer islands could attend. The EPM workshop was attended by the Public Health Physician, who formulated a well-structured way to overcome the identified barriers under the headings of: training and education, funding, human resources and system improvement.

What next?

A return to Fiji in mid-2014 has been proposed, in order to support local instructors in running more EPM and EPM instructor workshops, as well as 'EPM-Lite' workshops for Fiji National University medical students. The healthcare professionals in Tuvalu are also keen to have ongoing support and for a further visit in 2014 if possible.

As we do these courses and meet more of the local professionals, we are finding that a number of 'champions' are emerging, who are passionate about managing pain and also in looking after palliative patients. We have so far run palliative care workshops alongside the EPM workshops in Lautoka, Fiji and also in Rarotonga, Cook Islands. Requests are growing to run more palliative care workshops, although the task of securing funding for these is still a work in progress.



EPM courses are run in many developing countries. If anyone is interested in being part of this initiative, please email **Linda Huggins:** linda.huggins@middlemore.co.nz

For more information, please go to www.essentialpainmanagement.org

Top: EPM workshop participants at the Princess Margaret Hospital, Tuvalu (23–24 October, 2013). **Above:** EPM workshop in Suva, Fiji (October 2013).

This article was first published on ehospice (www.ehospice.com) as 'Essential Pain Management in the Pacific' on 28 November 2013. Adapted and reused with permission from the author.

PACIFIC FOCUS

Palliative care training in Samoa: 7–15 April 2013

By Sue Marsden, palliative medicine specialist, Otago Community Hospice, and Liese Groot-Alberts, grief therapist and palliative care educator, Auckland

Background

Our introduction to working in Samoa followed the devastating tsunami in 2009. Over a two-year period, we worked with Women in Business Development to provide post-trauma grief and bereavement support and training for their staff and clients.

Quite separately, we were invited by Oceania University of Medicine (OUM) in 2010 to support the development of palliative care in Samoa and to help introduce palliative care into their curriculum. Accordingly, an inaugural five-day palliative care workshop was held in February 2011 to gauge the interest for palliative care. Forty-five people attended the workshop, which was opened by the Samoan Minister of Health and the New Zealand High Commissioner. One of its goals was to form a steering group, consisting of representatives from the Samoan National Health Service (SNHS), OUM and the community, which would plan and support the development of palliative care in Samoa.

Unfortunately, due to difficult changes in OUM and staffing problems at the hospital, OUM support for the project was no longer possible and the steering group faltered. However, it was kept alive by volunteers in the community, who saw joining the Samoan Cancer Society (SCS) as the way forward. Thus a palliative care arm of SCS was formed, with a remit to support all patients with palliative care needs (with or without cancer). With a focus on the community, this group employs two nurses to provide education and coordinate care, while working closely with SNHS community

nurses, who perform the 'hands-on' aspects of care.

The visit

The Palliative Care Training visit to Samoa between 7–15 April 2013 was initiated and funded through Counties Manukau District Health Board (CMDHB) to provide training to SNHS, in conjunction with the Essential Pain Management training provided by **Linda Huggins, Margaret Tuala and Michal Kluger**. The planned program included five days in Apia and one day on Savai'i, dovetailing with the Essential Pain Management workshop. The visit and training was organised in conjunction with SCS.

The teaching team consisted of:

- **Liese Groot-Alberts**, grief therapist and palliative care educator from Auckland
- **Sue Marsden**, palliative medicine specialist with Otago Community Hospice
- **Joyce Roache and Siumatautu Tapelu**, both registered nurses with the Samoan Cancer Society, and
- **Janet Mikkelsen**, paediatric palliative care nurse with Auckland District Health Board.

Community workshop

This workshop was held on 8 April at Mapuifagalele, a rest home for the elderly run by the Little Sisters of the Poor. It was attended by 19 participants including cancer patients, family members, carers, other interested members of the public, sisters and nurses. Translation, which was needed at this workshop, was provided by **Si'u Tapelu** from SCS.

The workshop focused on introducing palliative care concepts, including grief and bereavement. Small group discussions were held around the experience of palliative care in Samoa

and how this could be improved. **Amanda Lam** from the SCS executive described the role of her organisation in providing palliative care.

Health care worker workshops

Two one-day workshops aimed at health care workers were held on 9 and 10 April. Each had 13 attendees, who were invited from SNHS and included doctors, nurses, dieticians, pharmacists, physiotherapists, as well as a biomedical scientist and a healthcare manager (with a dentist background!).

The two workshops had a similar format, with an introduction to palliative care concepts, group discussions around the groups' experiences of palliative care in Samoa, symptom management and emotional and spiritual aspects of care. Once again, **Amanda Lam** from SCS discussed the role of her organisation in the delivery of palliative care in Samoa.

Both groups were enthusiastic and the sessions were very interactive. The mix of disciplines present was helpful in discussing and modelling the multidisciplinary nature of palliative care delivery.

The positive aspects of care in Samoa were emphasised: the strength of family ties and support, the strong faith-base in the culture and familiarity with death. Challenges to the provision of care focused around health infrastructure, funding, the availability of medication and other resources in the community, as well as persistent myths surrounding health care. The critical need for educating healthcare professionals as well as the general public was identified. This included knowledge of what constitutes good palliation and should thus be expected, symptom management and counselling skills.

A short workshop was also held at the hospital at Savai'i on 15 April. This was well attended by hospital and community staff with some 35 participants – with extra participants attempting to join in from the doorway!

PACIFIC FOCUS

The workshop focused on introducing the concepts of palliative care, pain management and grief and bereavement. Information about the Cancer Society's role was also given. The group was engaged and enthusiastic, with a thirst for knowledge. Unfortunately, there was no time for small group discussion at this workshop.

Other activities

- We reviewed a young boy with advanced metastatic retinoblastoma at the SCS rooms, whose disease had progressed despite treatment in Auckland. Medical follow-up was limited by the poor local medical infrastructure. It was also difficult to establish whether his older sister, who has had an eye injury, had been screened retinoblastoma. CSC is providing ongoing support for his family and coordinating care, and the visiting team has also offered to provide ongoing phone support.
- We were interviewed by the local paper *Samoa Observer* for an article on palliative care, with the goal of raising public awareness.
- We also met with local GPs, who discussed the tension between SNHS and independent GPs, ongoing difficulties with the availability of medications and the overwhelming workloads of

community nurses. A thirst for symptom management training was expressed by the GPs, who were encouraged to attend the Essential Pain Management workshop.

- Daily debriefing meetings were held, with emphasis on facilitator feedback, future needs for palliative care education and the support which might be required to help establish better palliative care services in Samoa. Sessions were held with SCS staff and also separately with visiting consultant staff.

Reflections and recommendations

- We confirmed the view that there is an urgent need for good palliative care training and service and policy development in Samoa, and that a genuine enthusiasm for this to happen exists at a 'grassroots' level in the community and also from younger healthcare professionals within the SNHS. However, there seem to be persistent barriers within SNHS infrastructure with respect to basic healthcare delivery and hence delivery of palliative care. Review of the drug formulary, with the addition of at least long-acting morphine, is a must.
 - It is important for outside consultants to remain respectful of systems
- operating in Samoa and maintain a purely supportive role, encouraging the establishment of palliative care resource roles from within the Samoan healthcare community. Regular visits by a stable team, organised through SNHS and SCS, may assist in establishing a trusting relationship. Visits to Community Health Centres around both islands, with the offer of combined patient visits with community staff, would also be helpful.
 - The palliative care group within SCS has established itself as a vital support in the community by providing professional advice, as well as coordinating care. Importantly, they are careful not to provide hands-on care, which is already being delivered by SNHS community nurses. The SCS needs to be supported and encouraged in its role.
 - Symptom management and communication skills were identified as key priorities in terms of skill-based education. Workshops on these topics should be held in Apia and Savai'i.
 - The identification, appointment and training of palliative care medical and nursing leaders by SNHS is another priority. **Viali Lomeko**, a doctor working at both Tupua Tamasese Meaole Hospital (the main hospital in Samoa) and OUM, will be coming to CMDHB for a three-month palliative care placement later this year. Unfortunately, he was unable to attend any of the workshops. It is suggested that similar training placements be made available for key nursing and medical staff in the future.



Acknowledgements: We would like to acknowledge the help and support of all the staff of the Samoan Cancer Society (especially **Amanda Lam**). We would also like to thank CMDHB for their support and funding for the trip and **Linda Huggins** and **Janet Mikkelsen** for their contribution and support.

Left: Community workshop at Mapuifagalele.

PACIFIC FOCUS

New Zealand Pacific Palliative Care Network

By Sara Rishworth
Palliative care specialist
Mercy Hospice Auckland

NEW ZEALAND PACIFIC Palliative Care Network (NZPPCN) is a loose network of people who have an interest in the provision of palliative care in the Pacific and to Pacific people in New Zealand. Involvement has been by word of mouth and there is no formal membership.

For the last two years, we have been meeting around four times per year in Auckland, New Zealand. A number of network members also keep in touch by email.

We saw our primary goal as providing a forum where those already visiting countries in the Pacific touched base with each other, so there was less duplication and some coordination of what was offered. In addition, we hoped to support staff already

providing for palliative care needs of individuals in isolated situations, through phone and email support with an appropriate clinician. Practical support and advocacy were also key objectives.

The size of the group has varied between five and fifteen people and we have managed to achieve a few of these aspirations in a number of areas. The strengths of the network have been connecting people up and beginning to build relationships with specific people on the ground in Tonga, Samoa, Fiji and the Cook Islands. The main challenge has been accepting the limitations of a network and appreciating what can be done – even if it's only on a small scale.

If you are interested in joining NZPPCN, please email Sara Rishworth at sara.rishworth@mercyhospice.org.nz

ANZSPM Position Statement on Quality End-of-Life Care – Part 1

◀ Continued from page 1

of life for patients and their families', leaves many patients and families enduring unnecessary and prolonged suffering at the end of life. This 'traditional model of care' may also leave many clinicians feeling that they are 'failing' their patients. Alternative and concurrently applied EoL Care models could help with enhancing patient choice and Quality of Life (QoL) as well as increasing family and clinician satisfaction.

...our species' epochal success in staving off death impacts contemporary individual and communal life in ways we have yet to understand. Prolonged serious illness, physical dependence, senescence and senility are now common facts of late life. Our society and culture must factor this new normal 'waning stage of life' into our expectations and plans. It isn't easy to 'die well' in modern times. Because so many treatments



work, many people survive longer with several previously lethal conditions. Clinicians now talk of a patient's 'illness burden', a term for the accumulated aches, pains and disabilities that come with diseases and the side-effects of treatment. As odd as it may sound people are sicker before they die today than ever before.

– Author: Dr Ira Byock, *Best Care Possible* (Penguin 2012)

In response to an increasing burden of chronic disease and an ageing population, there has been an emergence of new models of interdisciplinary care, termed subacute care (Rehabilitation, Geriatrics Evaluation and Management, Psychogeriatrics and Palliative Care). Geriatrics and Palliative Medicine share in common the management of patients in both acute and subacute phases of their illness episodes. In these sub-populations, a shared decision-making approach is important and it is essential that goals of care are discussed and negotiated with patients, families, loved ones and carers. However it is necessary to recognise that in the absence of consensus it is the decision of the patient (or patient's guardian or 'person responsible' if the patient is 'incompetent') that must prevail. It is also important that QoL be understood from the perspective of the patient. Any EoL Care Plans need to be clearly

documented with appropriate and transparent outcome measures put in place, even when they involve concurrent, time-limited trials of active disease-modifying management. However, the predominant culture throughout much of our healthcare system and society in general, continues to focus on 'curative' care and 'life prolongation' exclusively, at almost any cost. Many clinicians, patients and their families see adopting a concurrent 'palliative approach' or a referral to Specialist Palliative Care even for 'shared care' as an 'admission of defeat'. Instead, a referral for Specialist Palliative Care advice at the EoL should be seen as a way for patients, families, loved ones, carers and clinicians to ensure that 'best care possible' is being delivered when there is natural progression of a chronic disease process. In other words – **Right Care, in the Right Place, at the Right Time:**

- **Right Care** – EoL Care that focuses on enhancing the Quality of Life for patients and families facing issues associated with the end of life.
- **Right Place** – EoL Care can often be provided in the patient's 'Preferred Place of Care' if coordinated care and support infrastructures are put in place across clinical teams, settings and time.
- **Right Time** – in the last 6–12 months of life multidisciplinary and coordinated EoL Care focusing on QoL enhancement is vital and this can be given in conjunction with disease modifying treatments to achieve the best patient-centred outcomes.

Definitions

Various definitions for 'Care Types' need to be clarified to avoid confusion for patients, their families/loved ones, carers and clinicians facing the final phases of a patient's illness journey. Some of these terms can be confusing if they are used interchangeably, without clarification and are not clearly focused on outcomes. These

outcomes need to be measured to ensure that 'best practice care' is being delivered at any time. Three areas that need clarification are:

1. Palliative Care
2. Quality End-of-Life Care
3. Specialist Palliative Care

1. Palliative Care

Palliative Care even applies to non-specialist care and is defined by WHO (2013)¹ as:

...an approach to care that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care also respects the choice of patients and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement.

Quill & Abernethy (NEJM 2013)² suggest that Primary Level or Non-Palliative Medicine Physician delivered Palliative Care should be able to manage:

- Basic pain and other symptoms
- Basic depression and anxiety
- Basic discussions about: Prognosis, Goals of Treatment, Suffering, Resuscitation Code Status.

2. End-of-Life Care

End-of-Life Care is defined:

(a) by the Health Performance Council of South Australia (2010):

...as care provided to people who are experiencing a condition which will eventually be fatal. EoL Care can be provided by all health care professionals and is not limited to Specialist Palliative Care services. Quality EoL Care is realised when strong networks exist between Specialist Palliative Care providers,

primary generalist providers, primary specialists, support care providers and the community – working together meets the needs of people requiring EoL care.

and

(b) by the National Council for Palliative Care (UK – 2006):

...Care which helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

3. Specialist Palliative Care

Specialist Palliative Care is defined:

(a) by Palliative Care Australia (2008) as:

...services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in various care settings including community, home, hospitals, aged care homes and hospices and palliative care units.

(b) more specifically by Quill & Abernethy (NEJM 2013) as:

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment: within families, between staff and families, among treatment teams

Continued on page 10 ►

ANZSPM Position Statement on Quality End-of-Life Care – Part 1

◀ Continued from page 9

- Assistance in addressing cases of *inappropriate care that some may define as 'near futility'*

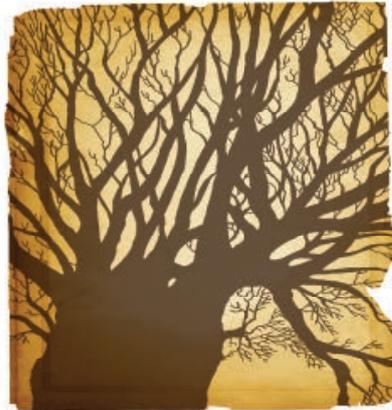
and

(c) in the New Zealand Palliative Care Glossary (January 2012)³ as:

palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care is delivered in two key ways in accordance with New Zealand definition of Palliative Care.

- *Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.*
- *Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the*



generalist provision of palliative care provision.

(d) In addition, the Society of Palliative Medicine (UK) states that expected deaths make up 62– 83%⁴ of all deaths and that the Specialist Palliative Medicine workforce is currently too small to be able to care for all of these patients and their families, loved ones and carers, even though this would be highly desirable. Hence, a significant part of the role of any Palliative Medicine Physician (30–50%) needs to encompass many non-clinical components including capacity building of the Generalist EoL Care Workforce (GPs and Non-Palliative Medicine Specialists).⁵

Statement

ANZSPM believes that Quality EoL Care requires both integration and coordination of our health care system and the delivery of quality, appropriate, safe, holistic care at the end-of-life. Best practice care must always include the measuring of clearly defined patient and family-centred outcomes. Palliative Care and Quality EoL care are everybody's business.

The Four Essential End-of-Life Care Processes

ANZSPM emphasises that some overarching principles should be applied to guide all EoL Care and these should include the following four processes:

- 1. Delivery of EoL Care that is holistic and interdisciplinary in nature that:**
 - (a) focuses on enhancing QoL for the patient as perceived by the patient and their family, their loved ones and carers;
 - (b) is based on impeccable assessment of symptoms that include physical, cognitive, psychological, social and spiritual domains; and
 - (c) includes documented Care Plans for families, loved ones and carers.
- 2. Development and documentation of proactive, individualised/flexible Care Plans** that can be easily accessed by relevant treating teams across time and settings.
- 3. Frequent and timely re-assessment with documentation of reviewed Care Plans.**
- 4. Measurement and documentation of appropriate and agreed outcomes** – as it is essential to know that 'quality outcomes' are being delivered and that referral to Specialist Palliative Care takes place in a timely manner where necessary.

The Five Domains of End-of-Life Care

Further to this, ANZSPM has conducted an extensive literature review looking for major evidence-to-practice gaps in EoL Care.⁶⁻⁸ The goal was to develop a suite of generic EoL Care Clinical Indicators with clear outcome

measures focused around ensuring that EoL Care was of the quality necessary to be delivering appropriate patient and family outcomes in the last 6–12 months of life, irrespective of the EoL Care provider (Generalist or Specialist). Where desired outcomes were not being achieved then timely referrals would become a natural process to ensure 'best care'. The five major domains of current EoL Care evidence-to-practice gaps that were identified are:

- 1. Symptom management (holistic and multidisciplinary)** – especially focusing on pain, shortness of breath, anxiety and depression, plus managing spiritual and/or existential distress. This process should be evidence-based and include a careful search for treatment side-effects or drug interactions and putting mitigating strategies in place (e.g. proactively manage constipation, nausea, cognitive impairment, fatigue, decreased function; reduce the risks of poly-pharmacy and institute rational de-prescribing processes based on harm/burden vs. benefit in the context of a realistic prognosis).
- 2. Advance Care Planning** – especially identifying patient-selected *Substitute Decision Makers*, documenting shared 'goals-of-care', patient preferences for treatment options and *Preferred Place of Care*, documenting appropriate Resuscitation Plans.
- 3. Carer Support** – documenting a list of close family members, loved ones and carers, and developing documented, evidence-based support plans for them that include bereavement follow-up plans, by use of appropriate validated bereavement risk assessment processes.
- 4. Coordination and Integration of Care** – across clinical teams, care-settings and time; instituting processes for safe, easily accessible and timely Clinical Handover;

Regional Registration of EoL Care and/or Palliative Care Patients – to allow for optimal tracking and coordination of care by identified care planning teams; more timely access by all treating teams (primary care and non-palliative care specialists) to Specialist Palliative Care for advice when needed. It should also include any currently applicable clinical and care planning documentation; this process must also include plans for adequate access to appropriate community pharmacy services in a timely manner (e.g. opioid and other essential EoL Care pharmaceutical supplies and appropriately skilled Home Medicines Review).

- 5. Terminal Phase (last 7–10 days of life)** – timely recognition of the 'dying phase' and developing documented Terminal Phase Plans to adequately manage patients in their Terminal Phase and support their families, loved ones and carers.

It is ANZSPM's belief that any Quality EoL Care management process must include documented interdisciplinary or holistic Care Plans that cover the first four of these domains and when the 'Terminal Phase' is suspected, should also include plans documented in this last evidence-to-practice gap domain for providing timely and quality Terminal Care as well.

Conclusion

ANZSPM feels very strongly that Quality EoL Care is of the utmost importance and achievable for all patients, carers and families in Australia and New Zealand. All primary care and specialist providers, patients and families should have access to Specialist Palliative Care Services in all settings when Quality EoL Care outcomes are not being achieved. All clinicians (generalist to specialist) should be able to have easy access to regular, ongoing up skilling in 'best practice' EoL Care management. As life comes with a 100% guarantee of

mortality, we believe that basic Quality EoL Care management should be a mandatory part of the training and periodic re-validation process for any Specialist or Primary Care Physician who is likely to manage EoL Care patients, their families, loved ones and carers.

It is ANZSPM's firmly held belief that any Quality EoL Care management process must include documented Care Plans that cover the outlined major EoL Care evidence-to-practice gap domains.

In this EoL Care position statement we have outlined some current major evidence-to-practice gap domains for Quality EoL Care; we believe that EoL Care should be evidence-based and outcome focused.

ANZSPM believes that the five domains outlined should form the basis for further development of Quality EoL Care standards, minimum data sets, outcome measures, clinical indicators and clinician performance measurement sets to ensure 'best practice and up-to-date' EoL Care is being delivered to all patients, families, loved ones and carers facing the last 6–12 months of life.

A PDF version of this Statement can be downloaded from the publications section of our website at www.anzspm.org.au

References: **1.** Strengthening of palliative care as a component of integrated treatment throughout the life course WHO Exec Board Report EB 134/28 Dec 2013. **2.** Quill TE and Abernethy AP. Generalist plus Specialist Palliative Care – creating a more sustainable model. *NEJM* Mar. 2013; 368:1173-1175. **3.** New Zealand Palliative Care Glossary January 2012, Published by The Palliative Care Council of New Zealand, Hospice New Zealand & the Ministry of Health. **4.** Hughes-Hallet T, Craft A, Davies C, Mackay I, Nielsson T. Palliative Care Funding Review: Funding the Right Care and Support for Everyone. 2011. **5.** Wee B et al RACP Palliative Medicine 2013 **6.** ANZSPM Clinical Indicators for EoL and Palliative Care 2010. **7.** Lorenz K, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for improving palliative care at the end of life: a systematic review. *Annals of Internal Medicine*. 2008 Jan 15;148(2):147-159. **8.** Qaseem A, Snow V, Shekelle P, Casey DR Jr, Cross JT Jr, Owens DK, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Annals of Internal Medicine*. 2008 Jan 15;148(2):141-146.

JOURNAL CLUB

'Comparison of Survival Analysis and Palliative Care Involvement in Patients Aged Over 70 Years Choosing Conservative Management or Renal Replacement Therapy in Advanced Chronic Kidney Disease'

Authors: JA Hussain,
A Mooney and L Russon.

Palliative Medicine
2013;27(9):829-839.

Study summary

By Chi Li
Advanced trainee

Design

- Retrospective, observational, single centre.

Population

- Patients attending a pre-dialysis clinic located in West Yorkshire, UK.
- Inclusion:
 - Age > 70 years.
 - Gradual decline in renal function (eGFR <20ml/min).
- Exclusion:
 - Insufficient time to make an informed treatment choice: presented with stage 5 chronic kidney disease, rapid decline in renal function, unexpected early death.
 - Renal function improved, transplantation.
 - Remained undecided regarding treatment.

Intervention

- Participants offered both renal replacement therapy (RRT) and conservative management (CM).
- Decision-making process included in-depth discussions with physicians and specialist nurses (who visit the patient's home),

written information, and further discussion with members of the multi-disciplinary team (MDT) as required.

- Average time to make decision was 53 days (range 0–824 days).
- Once decision made, management identical until the development of symptomatic uraemia, upon which the RRT group commenced dialysis, while the CM group continued best supportive care as detailed below:
 - Ongoing regular review at the clinic by the MDT, which included clinical nurse specialists, dieticians and social workers, as well as a palliative physician, with the support of a renal physician.
 - Management of fluid and electrolyte balance, anaemia and bone disease identical to those choosing RRT.
 - Greater emphasis on quality of life, symptom control and advanced care planning.

Data collection

- Study duration: September 2006 to December 2010
- Data collection: January 2011 to May 2011
- Data collected by a non-specialist researcher with no previous contact with patients
- Measurement instruments
 - Comorbidity: Davies co-morbidity scores and Charlson's Comorbidity Index (CCI)
 - Functional status: World Health Organization (WHO) performance score

Data analysis

- Incomplete data coded as missing data.
- Intention-to-treat analysis.
- Statistical significance defined as $p < 0.05$.

Results

- 441 patients included: 269 chose RRT and 172 chose CM.
 - Crossover: 19 patients from RRT group changed to CM; 3 patients from CM group changed to RRT
 - In the RRT group, 53 patients (19.7%) died before commencing dialysis, 80 patients (29.7%) still had not commenced dialysis at the end of the study
- Patient demographics and clinical characteristics:
 - CM group was older than the RRT group (mean age 88 versus 77 years, $p < 0.001$)
 - Compared to RRT group, CM group significantly more likely to:
 - Have lower albumin, diabetes, hypertension, chronic lung disease and dementia
 - Have a higher CCI score (but no difference in Davies co-morbidity scores)
 - Have poorer performance status, be institutionalised or live with family who were their primary carers
- Survival (time from eGFR <20 mL/min to death)
 - Overall, RRT group survived longer than CM group ($p < 0.0001$)
 - Other risk factors for death: age, CCI score, WHO performance score, living independently

- In patients older than 80 years old or with a WHO performance score ≥ 3 , no difference in survival between the two groups
- Hospital admission
 - Higher risk of hospital admission in the RRT group: relative risk 1.6 (95% CI 1.14-2.13, $p < 0.05$)
- Death in hospital
 - CM group: 47% (36/76 patients)
 - RRT group: 69% (registry data)
- Specialist palliative care services
 - Access to community palliative care: CM 76% versus RRT 0%
 - Palliative care physician review: CM 85% versus RRT 4%
 - Social worker review: CM 37% versus RRT 34%

Invited expert commentary on the renal replacement therapy versus conservative management paper

By Frank Brennan, Palliative care physician, Department of Nephrology, St George Hospital, Sydney

THIS STUDY JOINS a small but growing body of literature examining a basic, indeed threshold, question in the management of elderly patients with end stage renal failure: Is commencing dialysis the right thing to do? For some time, the assumption was that dialysis would always provide a survivorship advantage over a conservative or non-dialysis pathway. The results of a series of studies commencing with a paper by Fliss Murtagh and colleagues have challenged this orthodoxy.¹ In summary, those studies show that, in elderly patients, dialysis does give a survival advantage over conservative management but that this advantage is eliminated in the

presence of significant co-morbidities, especially ischaemic heart disease. In other words, an elderly patient who has concurrent end stage renal failure and other significant co-morbidities, especially ischaemic heart disease, may not necessarily live longer on dialysis than on a conservative pathway. Carlson and colleagues also found an interesting addendum to these findings – that, in this elderly cohort, virtually the entire survival advantage time of the dialysis cohort is spent in hospital on dialysis or as an in-patient with complications of their illness or its treatment.²

This is a retrospective, observational study examining patients over 70 years in age with chronic kidney disease and an eGFR less than 20. The study compares those patients who commenced dialysis and those who chose a conservative pathway. Consistent with the studies cited above, renal replacement therapy did not provide a survival advantage when significant co-morbidities were included. Indeed, the study found that no advantage accrued in two situations – if the patient was, at the time of decision making, older than 80 years and the WHO performance status was 3 or less. The latter represents being ‘capable of only limited self-care, confined to bed or chair more than 50% of waking hours’.

The study’s findings are consistent with its predecessors. Equally, it reinforces the guidelines on shared decision-making in the initiation and withdrawal of dialysis published by the Renal Physicians Association of the USA in 2010.³ Those guidelines stated, amongst many recommendations, that it was reasonable for nephrologists to consider not commencing or ceasing dialysis in patients who were 75 years and above with two or more of the following criteria that have been statistically shown to be associated with poor prognosis:

- (a) high levels of co-morbidities
- (b) poor performance status
- (c) poor nutritional status

- (d) the Surprise Question – the clinician would not be surprised if the patient died in the next 12 months.

Further questions that are logically asked by patients and families are: if I am not to be dialysed, who will care for me and what will that care entail? These are important questions to which, over time, answers are emerging. In simple terms, the conservative management of a patient with end stage kidney disease is a combination of excellent renal medicine and palliative medicine. The former will involve careful monitoring of blood pressure, fluid status, haemoglobin and calcium and phosphate levels. The latter will involve symptom management, psychosocial support, advanced care planning and assistance in care of the dying patient. The second and third authors of this study have collaborated across these disciplines to create a conservative management programme. Through that programme patients on a conservative pathway had greater access to palliative care services and were less likely to be admitted to or die in hospital than their colleagues who had chosen a dialysis pathway.

An excellent Australasian summary of the deliberations in decision-making leading to the commencement of dialysis or a conservative pathway, and the respective roles of renal and palliative medicine in this area, is contained in an extensive position paper and guidelines on renal palliative care that was published in *Nephrology* in 2013.⁴

References: 1. Murtagh FE, Marsh JE, Donohue P, et al. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney diseases stage 5. *Nephrol Dial Transplant* 2007;22(7): 1955-1962. 2. Carlson RC, Juszczak M, Davenport A, et al. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol* 2009;4(10):1611-1619. 3. Renal Physicians Association of the USA. *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline*. 2nd edition, Rockville, Maryland, 2010. 4. Brown MA, Crail S, Masterton R, et al. ANZSN Renal Supportive Care Guidelines 2013. *Nephrology (Carlton)* 2013;18(6): 401-454.

JOURNAL CLUB

Prevalence, Impact and Treatment of Death Rattle: A Systematic Review

Authors: ME Lokker, L van Zuylen, CCD van der Rijt and A van der Heide.

Journal of Pain and Symptom Management 2014;47(1):105-122.

Study summary

By **Angela Plunkett**
Palliative care registrar
Queensland

Overview

IN 2008, a Cochrane review showed that there was no evidence that any intervention, pharmacological or nonpharmacological, was superior to placebo in the treatment of noisy breathing in dying patients.¹

This current study included a wide variety of study types from the four years (2008–2012) subsequent to the Cochrane review. All studies were published in English. The authors sought to answer three questions. Firstly, what is the prevalence of noisy breathing, or 'death rattle'? Secondly, how does noisy breathing affect patients, relatives and staff? And thirdly, what is the effectiveness of interventions?

A wide range of patients was included in this review. Thus prevalence varied widely across populations, from 12% to 92%.

Noisy breathing was found to be distressing to relatives and staff, but in view of the inclusion of studies focusing on dying patients only, its impact on patients remained unclear.

Like the Cochrane review before it, no evidence was found for pharmacological interventions for noisy breathing, and no studies looking at non-pharmacological remedies such as repositioning were included.

This summary uses the AMSTAR criteria to assess the quality of this new systematic review.²

1. Was an 'a priori' design provided?

The research questions were set up clearly at the start of the paper – namely, the prevalence of the 'death rattle', its impact on patients, relatives and professional staff, and the effectiveness of interventions to address the death rattle.

Inclusion criteria were also established before the review was conducted. The studies had to involve more than 50 adult patients, be written in English, be original research, and be concerned with the death rattle in the dying phase, rather than earlier in life.

2. Was there duplicate study selection and data extraction?

There were two independent data extractors for only ten per cent of the included studies. However, a consensus procedure for disagreements was in place and appropriate statistical methods for agreement (Cohen's kappa) were documented.

3. Was a comprehensive literature search performed?

A sufficient number of resources was searched, including PubMed, Embase, CINAHL, Web of Science and PsychINFO. The key words and MESH terms were also clearly stated. This search was supplemented by

hand-searching the reference lists of all included articles and relevant literature reviews, from 1998 up until August 2012.

4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?

The review included a range of study types, including randomised controlled trials, cohorts, case-control studies and cross-sectional studies. Qualitative studies, such as interview studies and focus groups, were also included. Of the 1,062 articles identified by the literature search, a total of 39 studies were included in the systematic review.

5. Was a list of studies (included and excluded) provided?

A list of included studies was provided. However, a full list of the excluded studies was not provided.

6. Were the characteristics of the included studies provided?

A table provided information on the authors, year of publication, setting (e.g. palliative care unit, hospice), study design and source of information (patients, relatives and staff members). This table also documents the outcome factors examined in each study (e.g. impact of death rattle on relatives, impact of interventions).

7. Was the scientific quality of the included studies assessed and documented?

The quality of the included studies was assessed using a tool not familiar to this writer.³ This tool assesses quality along nine different aspects including: abstract and title, introduction and aims, methods and data, sampling, analysis, ethics and bias, results, generalisability and

practical usefulness of the study. Each aspect was scored using a four-point scale, where 1 is very poor quality and 4 is good quality evidence. The sum of all aspect scores yielded a total score, which ranged from 9 (very poor) to 36 (good).

8. Was the scientific quality of the included studies used appropriately in formulating conclusions?

The authors state that 21 of the articles included in the systematic review were rated between very poor quality and poor quality.

9. Were the methods used to combine the findings of studies appropriate?

Given the heterogeneity of the study quality and type, individual study results are presented separately.

10. Was the likelihood of publication bias assessed?

It appears that unpublished studies were neither searched for, nor included. Thus, there is potential for publication bias in this review.

11. Was there a comment on potential for conflict of interest?

Yes, and none was disclosed by these authors.

References: 1. Wee B, Hillier R. 'Interventions for noisy breathing in patients near to death'. *Cochrane Database of Systematic Reviews* 2008;1:CD005177. 2. Shea BJ, Grimshaw JM, Well GA, Boers M, Andersson N, Hamel C, Porter AC, Tugwell P, Moher D, Bouter LM. 'Development of AMSTAR: a measurement tool to assess the methodological quality of systematic review'. *BMC Medical Research Methodology* 2007;7:10. 3. Hawker S, Payne, S, Kerr C, Hardey M, Powell J. 'Appraising the evidence: reviewing disparate data systematically'. *Qualitative Health Research* 2002;12(9):1284-1299.

Invited expert commentary on the death rattle paper

**By Caitlin Sheehan
Palliative care physician
Calvary Health Care
Kogarah, Sydney**

ROBUST RANDOMISED CONTROL trials at the end of life have historically been difficult to perform, and so have failed to inform evidence-based guidelines for symptoms such as death rattle. A Cochrane review into the treatment of death rattle included only four studies and concluded that there was no evidence to support the use of antimuscarinic medications in the management of this symptom at the end of life. The authors of this review aimed to cast the net wider by including lower levels of evidence to provide a 'comprehensive overview of the empirical studies' relating to various aspects of death rattle.

The authors must be commended on a thorough and clearly described search strategy, and for their approach to assessing the quality of each included article. However, what is clearly evident from the paper is the vast variation in methodology, study setting, and even the definition of death rattle used.

The wide variation in reported prevalence only highlights further the heterogeneity of these articles. The weighted mean prevalence of death rattle is reported as 35% (range 12–92%). Yet, if only prospective studies are included, this rises to 45%. It can be concluded that this is a common symptom, affecting many patients at the end of life, about which there are many unanswered questions.

The article goes on to explore the impact of death rattle on patients, family and caregivers, through a review of both quantitative and qualitative studies. It concludes that the impact of symptoms on patients remains unclear. Indeed, the subject is broached in only one study asking nurses to report subjectively on the impact on the patient. The general assumption stated within textbooks and guidelines is that the unconscious patient is unaware and therefore unaffected by the noise, yet this remains unsubstantiated.

When describing efficacy of treatments, it must be noted that this study did not include the two placebo-controlled trials included in the Cochrane review, as they are not published in English. However, it does include the most recent placebo-controlled study of sublingual atropine. Although it is a negative study (demonstrating no benefit from the intervention), this important study begins to unravel the natural history of death rattle and proves that conducting adequately powered, placebo-controlled, randomised trials in this population is possible.

This review article highlights the dearth of information and understanding of this symptom and its management. While asking us as clinicians to question our well-ingrained practice of administering antimuscarinic medications, the authors call for urgent studies to inform the pharmacological and non-pharmacological management of death rattle.

ANZSPM

President's report

◀ Continued from page 2

on the Palliative Care Clinical Studies Collaborative Scientific Committee. Janet has recently resigned this position and we welcome **Jenny Philip** as our new representative to the role.

The work of the End-of-Life (EoL) Working Group (chaired by **Rohan Vora**) has come to fruition, with the publication of the new *ANZSPM Position Statement on Quality End-of-Life Care – Part 1: Essential elements for quality, safety and appropriate clinical care at the end of life*. This work will have a significant impact in Australia and hopefully in a number of other jurisdictions and services, particularly as the Australian Commission on Safety and Quality in Health Care has asked us to provide feedback on the *Draft National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care in Acute Hospitals*. We are grateful to our EoL Working Group for its efforts to date, as well as its ongoing work to develop supporting documentation that can further elucidate the translation of essential elements into practical clinical practice.

Two other groups, the newly established Palliative Sedation Working

Group and the reforming Workforce Strategy Working Group, have a number of willing members who will shortly begin addressing the specific tasks of each group.

ANZSPM has developed a position statement on the timely referral of patients with progressive solid tumours to specialist palliative care services. This has been reviewed and supported by the Medical Oncology Group of Australia. ANZSPM is yet to publicly release the statement and is considering a joint release in May ahead of National Palliative Care Week and RACP Congress. We thank **Carol Douglas** for her work in developing this statement.

ANZSPM is founding member of Palliative Care Australia (PCA). **Richard Chye**, as an independent member, was recently elected to the PCA board. Michael Chapman and I sit on the PCA National Policy Advisory Council and Marita participates in the member organisation joint meetings of executive officers. PCA is going through a significant process looking at rebranding and connecting with the Australian community. You may be asked to comment on this process as interested members through your state-based palliative care organisations. While ANZSPM will continue to maintain its

identity representing our members across Australia and New Zealand, cobranding with PCA for joint activities may become more explicit in the future. We look forward to all of PCA's work coming to fruition in the next few months.

ANZSPM continues to provide a number of educational activities. On the horizon are the ANZSPM 2014 Conference on the Gold Coast in September, two Trainee Days (Sydney in May and Gold Coast in September), three workshops at the RACP Congress in Auckland in May and the ANZSPM Aotearoa 2014 Annual Meeting in Wellington in June. Council has also agreed to support the development and hosting of a Spiritual Care online training package, which **Doug Bridge** has been working on for a number of years, in discussion with the RACP Chapter of Palliative Medicine. It's great that ANZSPM can assist in facilitating this educational development. Unfortunately, the successful ANZSPM Palliative Care Forums will not be taking place this year. We rely on sponsorship to hold these forums, but sponsors have not been as forthcoming in 2014 – but we will renew our efforts next year!

Council is only too aware of our current reliance on sponsorship to remain financially viable. There is consensus among New Zealand and Australian Council members to look for ways to reduce this dependence in the long term. A number of strategies are being examined. Our engagement with the Advisory Services project is a case in point – projects such as this can help raise ANZSPM's profile and lead to an increase in income. A review of current membership fees and structure is also being considered. Additionally, not only do we need to ensure that all members pay their fees in a timely manner, we also need to keep talking to our advanced trainees and diploma candidates about the benefits of our organisation, encouraging them and other specialists and generalists interested in palliative care to join us.

The momentum is well and truly forward. I look forward to your ongoing support and participation as the year unfolds.

ANZSPM Aotearoa Branch Chair's report

◀ Continued from page 3

In mid-February, we distributed to New Zealand media our support for **Ross Drake** (paediatric palliative medicine specialist at Starship Children's Hospital in Auckland) and the International Children's Palliative Care Network publication of the Mumbai Declaration. This international statement opposing euthanasia of children received BBC and Italian national television coverage, as it was released while the Belgian parliament was voting in favour of child euthanasia. **Emily Chang** (paediatric palliative medicine specialist) will be

our guest participant at the March executive teleconference.

We continue to maintain strong relationships with the Palliative Care Council and Hospice New Zealand. We strongly encourage registrars and advanced trainees in palliative medicine to submit research abstracts for our annual meeting. We will be delighted to hear from ANZSPM Aotearoa members who are interested in joining the executive in 2015.

Once again, may I thank doctors throughout Aotearoa New Zealand for the generosity of spirit, resilience and kindness with which they care for people who are dying and support their grieving families. *Kia Kaha. Gach Dea Gui.*

Permanent or Locum Consultant/Specialist posts in Palliative Medicine

Auckland Hospital Palliative Care Service

Job Reference: 061673 – Two positions

The Auckland Hospital Palliative Care Service is looking for two permanent or locum Consultant/Specialist posts in hospital palliative medicine. One position is available to start immediately.

Auckland Hospital is a large tertiary institution and is a teaching hospital of the University of Auckland with active undergraduate and graduate programs. You will have the opportunity to work in a palliative care team that includes Nurse Specialists, a Nurse Practitioner, Advanced Trainees, rotating registrars and end-of-life care facilitators. The team is actively involved in teaching and research activities as well as service development projects regionally and nationally.

To apply for this specialist post you require FACHPM qualification or a recognised equivalent (i.e. have completed at least a three–four year advanced training programme in Palliative Medicine) and must be eligible for registration with the New Zealand Medical Council. For details regarding registration, please visit www.mcnz.org.nz

In addition to a great job, the natural beauty of Auckland and New Zealand offers you a wide range of lifestyle opportunities including sailing on the Auckland Harbour, easy access to many beaches, the New Zealand native bush and snow-covered mountains.

ADHB is an accredited employer with NZ Immigration service so we can help with your immigration requirements and can also provide relocation assistance.

For further information about the position, please contact Dr Anne O'Callaghan, Clinical Director on anneo@adhb.govt.nz

Please apply online at www.careers.adhb.govt.nz and quote job reference number 061673 to attach your updated CV and a covering letter.

For assistance or a copy of the position description, please contact Esther Bathula, Recruitment Consultant on +64 9 639 0211, email: esther.bathula@adhb.govt.nz

Closing date: Friday, 30 May 2014

ANZSPM 1427

Locum Consultant Northern Adelaide Palliative Service

27 April – 15 June 2014

This is an ideal opportunity for a medical specialist to work as a member of the Northern Adelaide Palliative Service multidisciplinary team in close liaison with other service providers.

You will provide support and educative palliative care services including medical services to inpatients and outpatients at Modbury Hospice and the Lyell McEwin Hospital, as well as patients in community outreach programs within the Northern Adelaide catchment area.

You will hold appropriate specialist qualifications for a consultant and be registrable as a specialist with the Medical Board of Australia.

Skilled in problem solving and decision making at both the clinical and the individual level, you will have a high level of ability in negotiation and communication. You will demonstrate a commitment to patient and family participation in patient care, as well as a dedication to quality management philosophy and devolved responsibility.

You will be required to participate in the out-of-hours on-call roster and hold a current driver's licence.

For further information, please contact:

Lawrie Palmer
Medical Head of Unit
Modbury Hospital
Smart Road
Modbury SA 5092

lawrie.palmer@health.sa.gov.au
or 0407 843 994

ANZSPM 1430

ADVERTISEMENTS



**ANZSPM Aotearoa
2014 Annual Meeting
and Education Day
for members**

**14-15 June 2014
Brentwood Hotel, Wellington**

Highlights include:

- Networking with colleagues
- The Annual Debate
- Transitions between paediatric and adult palliative care by **Emily Chang** (paediatric palliative medicine specialist)

- COPD Update from **Rachel Wiseman** (respiratory and palliative medicine specialist)
- Undergraduate palliative medicine curriculum: is there one?

The program organisers are seeking:

1. Members who are keen to give a five minute report on highlights from any international conference of relevance during 2013/14, for the 'Round the World in 40 Minutes' session.
2. Trainee members who would like to present research/audit ideas/results – all trainees are encouraged to consider this opportunity.

Please come and share thoughts, ideas and questions with your fellow colleagues.

Registrations opening soon:

Check www.anzspm.org.au for details

**Anyone interested in contributing should contact:
Sinead Donnelly (ANZSPM Aotearoa Chair) via email: Sinead.Donnelly@ccdhb.org.nz**



**ANZSPM
Trainee Day
for palliative
medicine trainees**

**Friday, 16 May 2014
Sydney**

Another great Trainee Day has been planned for May. It will once again be a great opportunity to learn and to network with other trainees from across Australia and New Zealand.

Full program available soon at www.anzspm.org.au

To whet your appetite, some of the topics to be covered include:

- Recognising and treating anxiety and depression in patients at the end of life
- Transcultural issues at the end of life
- Pressures on health care professionals regarding euthanasia and assisted suicide
- Providing palliative care in residential aged care facilities

Please register online at www.anzspm.org.au

Places limited

No charge to attend

Lunch and morning and afternoon tea included

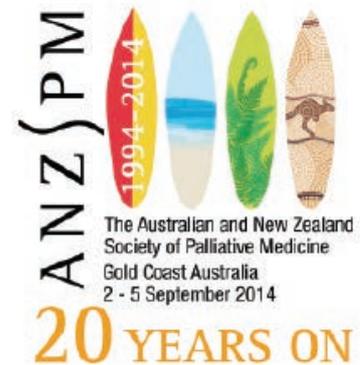
Enquiries to **Marita Linkson** – email executive@anzspm.org.au or phone **0458 203 229**

AUSTRALIAN AND NEW ZEALAND
SOCIETY OF PALLIATIVE MEDICINE

CONFERENCE

2-5 SEPTEMBER 2014

GOLD COAST, QUEENSLAND
AUSTRALIA



PALLIATIVE MEDICINE: PAST, PRESENT AND FUTURE

DESTINATION: GOLD COAST: The Gold Coast is one of Australia's leading holiday playgrounds and Gold Coast City has been identified as one of the most desirable places in the world to live. With 42 kilometres of sun-drenched beaches, World Heritage Listed rainforests, exhilarating rides, exotic animals and endless waterslides to help you cool off on hot summer days, the attractions of the Gold Coast bring smiles to people of all ages and stages.

SURFERS PARADISE is the celebrated heart of the Gold Coast, hosting national and international music, culture and sporting events, as well as being home to the largest nightlife district and some of the most luxurious accommodation in South East Queensland. It boasts a thriving local community and a reputation as one of Australia's favourite holiday destinations.



★ Registration & Call for Papers – NOW OPEN ★

★ Call for Papers deadline: 4 June 2014 ★

★ Early Bird registration deadline: 30 June 2014 ★

INVITED INTERNATIONAL SPEAKERS:



Professor Mike Bennett is the St Gemma's Professor of Palliative Medicine and Head of the Academic Unit of Palliative Care at the University of Leeds, UK.



Paul Glare MD is Chief of the Pain and Palliative Care Service and Attending Physician in the Department of Medicine at Memorial Sloan Kettering Cancer Center (MSKCC). He is also Professor of Medicine at the Weill Cornell Medical College, Program Director of the Hospice & Palliative Medicine Fellowship at MSKCC, and a fellow of the American College of Physicians.

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VENUE: SURFERS PARADISE MARRIOTT RESORT & SPA

The beautifully revitalised Surfers Paradise Marriott Resort & Spa is the Gold Coast's stylish playground for all generations. This breathtaking Gold Coast beach resort's location puts it within easy reach of pristine beaches, fashionable shopping precincts and picturesque hinterland valleys in Surfers Paradise, Australia. This Gold Coast hotel's accommodations are set amidst lush tropical gardens and feature cascading waterfalls, rock grottos, spas and the area's only private saltwater lagoon where guests can swim and snorkel with an array of tropical fish.

CONTACT: Conference Secretariat
PO Box 180, Morisset NSW 2264, AUSTRALIA
Tel: +61 2 4973 6573 • Fax: +61 2 4973 6609
E: anzspm@willorganise.com.au

**GOLD
SPONSOR:**



★ Conference website: www.anzspm.org.au/anzspm2014 ★

CONFERENCES & EVENTS

Conferences & Events Calendar

5th Biennial Palliative Care Nurses Australia Conference

Building a bridge to the future - the wide span of palliative care nursing

6-7 April 2014 | Sydney, NSW
www.pcna.org.au/conference

Stra Palliative Care Conference

10-12 April 2014, Palermo, Italy
www.bibacongressi.com (website in Italian)
Contact: congress@bibatour.it

National Palliative Care Week 2014

Sunday, 25 May-Saturday, 31 May 2014

SIPM Resilience Workshops

3-4 April 2014 (Advance Trainees)
7-8 April 2014 (Senior doctors, nurses & allied health)
Sydney, NSW
Email: SIPM@sswhs.nsw.gov.au

Delirium Masterclass - Medicine for Psychiatrists Conference 2014

4 April 2014 | Auckland, NSW
www.medicineforpsychiatrists.com/

Breathless - A Symposium on Breathing at the End of Life

11 April 2014 | Wellington, NZ
www.marypotter.org.nz/Breathless%20-%20Registration%20Form_11April2014.pdf

Australian Pain Society Annual Scientific Meeting

13-16 April 2014 | Hobart, Tas
www.dccconferences.com.au/aps2014/

Spiritual Care Australia National Conference

4-7 May 2014 | Adelaide, SA
www.spiritualcareaustralia.org.au

ANZSPM Trainee Day for Palliative Medicine Trainees

16 May 2014 | Sydney, NSW
www.anzspm.org.au

8th World Research Congress of the European Association for Palliative Care

5-7 June | Lleida, Spain
http://research2014.forskningsweb.org/

Cultural Diversity in Ageing 2014 Conference: Shaping Inclusive Services

12-13 June 2014 | Melbourne, Vic
www.culturaldiversity.com.au/conference-2014

ANZSPM Aotearoa 2014 Annual Meeting and Education Day for Members

★ SAVE THE DATES
14-15 June 2014 | Wellington, NZ
www.anzspm.org.au

SA Palliative Care State Conference

20 June 2014 | Adelaide, SA
www.pallcare.asn.au/news-events/news/sa-palliative-care-state-conference

6th Edition of the Singapore Palliative Conference 2014

26-29 June | Singapore
www.spccconference.com

Introduction to Pastoral Care and Ageing

30 June-3 July 2014 | Milton, Qld
Contact Kevin Teo, CAPS - kteo@csu.edu.au

Sapporo Conference for Palliative & Supportive Care in Cancer

11-12 July 2014 | Sapporo, Japan
www.sapporoconference.com/en/index.html

Living, Dying and Grieving Well - Palliative Care Victoria Conference 2014

31 July-1 August 2014 | Melbourne, Vic
www.pallcarevic.asn.au/conference

2nd Australian Palliative Care Research Colloquium

7-8 August 2014 | Melbourne, Vic
www.centreforpallcare.org

International Conference on End of Life: Law, Ethics, Policy and Practice 2014

13-15 August 2014 | Brisbane, Qld
http://icelconference2014.com/

ANZSPM 2014 Palliative Medicine: Past, Present and Future

2-5 September 2014 | Gold Coast, Qld
www.anzspm.org.au/anzspm2014



20th International Congress on Palliative Care

9-12 September 2014 | Montreal, Canada
www.palliativecare.ca/

World Hospice and Palliative Care Day 2014 Saturday 11 October 2014

www.zapaday.com/event/466875/2/World+Hospice+and+Palliative+Care+Day.html

New Zealand Population Health Congress:

6-8 October 2014 | Auckland, NZ
Abstracts close 29 May 2014
www.pophealthcongress.org.nz/nzphc14

ANZICS/ACCCN Intensive Care Annual Scientific Meeting 2014

9-11 October 2014 | Melbourne, Vic
www.intensivecareasm.com.au/2014/

21st Hospice New Zealand Palliative Care Conference

29-31 October 2014 | Wellington, NZ
www.hospice.org.nz/conference-2014

COSA 2014 (41st Annual Scientific Meeting for the Clinical Oncology Society of Australia)

2-4 December 2014 | Melbourne, Vic
www.cosa2014.org/

50 Shades of Pain Conference (Australian Pain Management Association and Palliative Care Qld)

3-5 December 2014 | Brisbane, Qld
www.50shadesconference2014.com.au/

11th Asia Pacific Hospice Conference

★ SAVE THE DATES
30 April-3 May 2015 | Taipei, Taiwan
www.2015aphc.org/