

Together! 2009 - welcome to Perth

In just over one week, Palliative Care Australia and the Asia Pacific Hospice Palliative Care Network will be welcoming more than 1,200 delegates from around the world to Perth for *Together! Cultural connections for quality care at the end of life*.

This joint conference, combining the 10th Australian Palliative Care Conference and the 8th Asia Pacific Hospice Conference is an historic event providing an unprecedented opportunity for collaboration and information exchange.

Our region is rich in knowledge and expertise in the delivery of quality care at the end of life, care that is provided by dedicated professionals in a range of contexts, across cultures and resourced to different levels. Whilst there is great diversity, what we all have in common is a desire to deliver the best care possible at the end of life, care that meets the needs of patients, families and carers.

More than 35 countries will be represented at *Together!* making it a truly international conference. Invited speakers from around the world include: Dr Stephen Connor, Dr Reena George, Ms Liese Groot-Alberts, Dr Elizabeth Gwyther, Professor Rod Macleod, Professor Sheila Payne, Dr M R Rajagopal, Dr Bernadette Tobin and Dr Bee Wee.

I am particularly proud of our significant conference bursary program which has allowed 27 delegates from developing countries to come to Perth and participate in the conference, contributing their unique insights and experiences to the conference mix.

The conference includes several social events which I encourage you to attend. These events offer us the opportunity to meet with our colleagues around the world, to make new friends and to build information networks to take forward the provision of quality care at the end of life.

I look forward to welcoming you to the conference.

Margaret O'Connor AM
President



Together!
Cultural connections for quality care at the end of life

In this issue

Together! 2009	2
PCA update	3
National end-of-life framework	
Parliamentary friends group	
Quality use of medicines	
National Aged Care Alliance	
NSAP update	
NSAP spotlight	
News brief	4
New dementia report	
NHMRC - ethics committee	
Healthy ageing	
Pallipedia	
PCA AGM and election	5
EoL - Towards quality care	5
PCAMO updates	6
Sector news	6
Conferences	6
PCA - responsibilities of office bearers	7
Contact details	8



PCA Connect





Together!

Cultural connections for quality care at the end of life

Perth Convention and Exhibition Centre
Perth—Western Australia
24-27 September 2009

The program

The full conference program for *Together! 2009* is now available. The program provides details of topics and presenters for each of the plenary and concurrent sessions. The conference sessions cover the breadth of palliative and end-of-life care and feature distinguished local and international presenters.

Each day of the conference features presentations around a key theme:

- palliative care for different populations
- present and future: challenges and opportunities in palliative care
- growing the workforce in palliative care.

Key program features:

- 132 speakers
- 52 concurrent sessions
- 5 hot topic Q&A sessions
- 5 challenging plenary sessions
- 2 exciting panel discussions
- 1 dynamic keynote presentation

Plenary session speaker – Shelia Payne

Professor Sheila Payne will be one of the plenary session speakers, addressing *The challenges of providing palliative care beyond cancer*.

Professor Payne is a health psychologist with a background in nursing. Since October 2006, she has held the Help the Hospices Chair in Hospice Studies based at the International Observatory on End of Life Care in the Division of Health Research at Lancaster University.

The focus of Professor Payne's presentation will be the challenges of providing palliative care for those with heart failure and stroke. These conditions are associated with high levels of mortality and morbidity, and can cause a wide range of distressing symptoms and problems. The presentation will highlight areas of unmet need in non-cancer patients and their families and consider the role of general and specialist palliative care in improving the quality of palliative and end-of-life care in these conditions.

Conference highlights

Palliative care at the movies

Date: Friday 25 September

Venue: Perth Convention Centre M2

Time: 1830-2030

Cost: free

We will be screening two films which offer insights into the end of life. *Russ' story - One man, one journey, many colours* is a profound documentary proposing that the energy and life of a person continues to live in the actions, memories and experiences of the community. The film maker Zoe Itzstein-Davey will be present at the session.

The second film is *Frankl's choice*. This film focuses on the life and philosophy of the great neurologist and psychoanalyst Viktor Frankl. With rarely seen archival film and video footage of Frankl (who died in 1997), this film provides an insight into the powerful messages this great humanist conveyed through his decades of teaching and writings.

Conference dinner and dance

Date: Saturday 26 September

Venue: Perth Convention Centre BelleVue Ballroom

Time: 1900-2330

Dress: semi-formal or national costume

Cost: included in full conference registration or \$132 for extra tickets

To honour the land that we call our home and to introduce all our international guests to the many wonders that make Australia so special, we are dedicating the *Together! 2009* conference dinner and dance to celebrating THIS IS AUSTRALIA!

The dinner will showcase the best in Australian fashion, food and music and will be followed by a night of dancing to a soundtrack of great Aussie tunes provided by one of Perth's leading bands.

Whilst we are celebrating our great country why not celebrate your own? All delegates are welcome to wear their national costume. Our large contingent of international guests will make this even quite a cultural connection.

For information on the conference, see

www.conlog.com.au/palliativecare2009

Palliative Care Australia - update

Policy report

National End-of-Life Framework forum

Palliative Care Australia will be providing the secretariat for a national forum of about 25 key opinion leaders from across the health sector to develop a National End-of-Life Framework. The national forum is planned for Thursday 15 and Friday 16 October 2009 at Government House in Canberra.

Overall, PCA is delighted with the recognition that palliative and end-of-life care has achieved in the context of health reform. However, we have realised that, despite these good intents, without a national end-of-life framework, it is not likely that the needs of patients will be reliably, effectively and efficiently met through fully-integrated services that recognise, protect and promote quality care at the end of life.

Health reform will shape the directions for palliative care in Australia. This forum is part of the development of Australia's first national end-of-life framework that will set the agenda and shape policy in the future.

A workshop at the *Together!* 2009 international conference in Perth will attempt to 'zero base' the planning for delivery upon the promise of quality care at the end of life for all Australians. We will start not with what currently is, but with what 'could be', from the perspectives of patients, families, carers and health professionals.

Parliamentary Friends of End-of-Life Care group

The new Parliamentary Friends of End-of-Life Care group got off to a great start with its first meeting on 18 August, with the primary points for discussion being preventable pain and palliative care. We have a good nucleus of Members and Senators across party divides who are keen to work with us towards better end-of-life care. The co-convenors are Queensland Labor Senator Claire Moore and Western Australia Liberal Senator Judith Adams.

We believe that the group will positively influence the awareness and thus the policies of the different political parties on the necessity to enhance the integration of palliative and end-of-life care within the whole-of-health system, which in turn will be important at election time.

Quality use of medicines and end-of-life care

The National Prescribing Service and PCA will launch our joint report *Achieving quality use of medicines in the community for palliative and end-of-life care* at the PCA conference in Perth at the end of September. Palliative Care Australia and the NPS will be disseminating two media releases nationally in the lead up to the launch.

The report will also be considered by the next meeting of the government's Palliative Care Medicines Working Group in October.

National Aged Care Alliance

At its last meeting, the National Aged Care Alliance finalised

a vision statement *Leading the way: Our vision for support and care of older Australians*. This statement has been fully endorsed by the PCA Board.

Palliative and end-of-life care is well represented in this statement, which envisions that a reformed care and support system will have a range of readily available support and care services linked seamlessly into the broader health system. These include: easily accessible primary health care services; transition care after any acute health episode so no-one has a long-term aged care assessment while acutely unwell; restorative and rehabilitative services to provide the greatest opportunity to return to full function after acute care; support and care services for people living with dementia; and palliative and end-of-life care.

There was also a very engaging and supportive session discussing current issues around palliative and end-of-life care.

National Standards Assessment Program

NSAP roll-out

The NSAP roll-out is well underway. The team is signing up services and planning the roll-out in more states and territories:

- services throughout Queensland are now commencing the 12-week self-assessment process
- the national paediatric cohort are beginning to formally register and start the self-assessment process
- New South Wales services attended the NSAP induction workshop on 13 August, are completing the final preparation stage of NSAP, and are beginning to formally register
- roll-out for South Australia, Victoria and Western Australia will commence in early 2010 and services in these states will be contacted individually prior to this time
- information for other states will be available from the NSAP website, future editions of *The Standard* newsletter and PCA e-bulletins.

If your state has already begun NSAP, you are still able to undertake the NSAP self-assessment - though you may not be completing it with your colleagues. Contact the NSAP team to discuss options for beginning NSAP at a later date if you have been unable to commence with your colleagues.

The Standard newsletter

The seventh edition of *The Standard* newsletter will be released this month and features further information on the self-assessment process. This edition's 'NSAP focus on quality' looks at the role of leadership in building a quality improvement culture.

The sixth edition is available for download from the [PCA website](#).

If you would like to be one of the first to receive future editions of *The Standard*, visit [PCA Connect](#) to have *The*

(continued p.4)

News brief

Dementia – the major disease of this century

Alzheimer's Australia has released a new report predicting the number of Australians with dementia will quadruple to more than 1.1 million by 2050. Dementia is a fatal disease and as yet there is no cure.

'Within our lifetime, neurodegenerative diseases, and in particular dementia, will overtake disorders such as cardiovascular disease and cancer as the major threats to Australian health and quality of life', said Lynne Pezullo, author of the report and Access Economics Director.

'If current trends continue through to 2060, spending on dementia will outstrip that of any other health condition, reaching \$83 billion and representing around 11 percent of all health and aged care expenditure.'

The report includes projections showing that reducing the number of Australians who are physically inactive by 20 percent would result in 6 percent fewer cases of dementia in 2050. Numbers would be reduced a further 6 percent by

National Standards Assessment Program

(continued from p. 3)

Standard delivered to your inbox automatically.

If you would like to contact the NSAP team or would like further information:

e: nsap@palliativecare.org.au

t: 02 6163 8419

To access the NSAP website, visit www.palliativecare.org.au and select the NSAP logo on the home page.

NSAP spotlight - The preparation phase

The preparation phase is the period between a service signing up and formally registering to begin the NSAP self-assessment process.

This phase is generally four weeks long and during this time services:

- attend the NSAP induction workshop (when participating with their state/cohort)
- receive the NSAP resources and begin to familiarise themselves with the tools and process
- Nominate
 - a liaison officer (day-to-day contact for the NSAP project team)
 - an executive sponsor (who supports the self-assessment process and officially registers the service to begin the self-assessment)
- begin to identify evidence for the self-assessment
- identify and invite people to be members of the multi-disciplinary self-assessment team.

Next month... Self-assessment – getting started

maintaining current trends in improvements in management of high blood pressure. The report finds a significant number of dementia cases might be prevented through lifestyle and health interventions.

The full report can be found at www.alzheimers.org.au.

National Health and Medical Research Council – ethics committee

Professor Margaret O'Connor, President of Palliative Care Australia, has been reappointed to the Australian Health Ethics Committee, a principal committee of the National Health and Medical Research Council.

The committee's role is to set and maintain standards of ethical conduct in health and medical research. It also has an important role in advising on ethical issues relating to health and the development of guidelines for ethical conduct of human research in Australia.

Palliative Care Australia congratulates all members of the committee on their appointments.

Healthy ageing

A national approach to aged care will be strengthened by the establishment of the Royal College of Nursing Australia - Health and Wellbeing in Ageing Faculty.

Chief Executive Officer, Debra Cerasa said, 'we want to change the perception that Australia's elderly population is sick and diminished.'

Healthy ageing can be a really positive process if it's underpinned by good health and lifestyle principles and preventative measures'.

The faculty will focus on promotion, development and research in the aged care sector and will be launched on 3 September at the college's conference.

More information is available at www.rcna.org.au.

Pallipedia from IAHPC

The International Association for Hospice and Palliative Care (IAHPC) has announced the launch of Pallipedia. Pallipedia is a free online palliative care dictionary to be built by the international community under the auspices of the International Association for Hospice and Palliative Care.

Pallipedia offers two options to visitors:

1. Searching for a term or concept related to the field of palliative care. The searching capability includes stop words and query language.

2. Submitting a term or concept related to the field of palliative care. Accepted terms and concepts are automatically indexed in alphabetical order.

The dictionary is housed at www.pallipedia.org.

PCA AGM election of president-elect

PCA wishes to advise that in accordance with the PCA Constitution (Section 11), election of president elect will occur at the 2009 Annual General Meeting.

Annual General Meeting 2009

Tuesday 17 November
PCA House
37 Geils Court
Deakin ACT

How is this position elected?

This position will be elected by secret ballot.

Who is eligible to vote?

Delegates to the PCA Council are eligible to vote for office bearers at a PCA Annual General Meeting.

Delegates to PCA Council who are unable to attend the AGM are permitted to appoint another council delegate or the chair as a proxy.

Who is eligible to stand as a nominee?

Nominees can be drawn from financial members of PCA member organisations.

Who is eligible to nominate?

Financial members of PCA member organisations are eligible to nominate.

How do I nominate?

Financial members must be nominated by 2 individuals both of whom are financial members of a PCA member organisation, and must provide written consent to the nomination.

Nominations are to be submitted on the PCA nomination form available from the PCA website and original signed copies are to be received by PCA **not later than 5.00pm, Tuesday 10 November 2009** and should be sent to:

The Public Officer
Palliative Care Australia
PO Box 24
Deakin West - ACT 2600

What are the responsibilities of elected office bearers?

The *Responsibilities of office bearers* information sheet is attached (p.7). Please consider this information when accepting or making a nomination.

Acknowledgement

The work of Palliative Care Australia is supported by funding from the Australian Government Department of Health and Ageing. For more information, see www.health.gov.au.

EoL – Towards quality care at the end of life

Is access to quality palliative and end-of-life care equitable for all Australians?

Equity is the focus of the soon to be released Spring edition of *EoL – Towards quality care at the end of life*.

Whilst comprehensive research on this issue is scarce, we do know people dying with cancer are significantly more likely to access specialist palliative care services than those dying with non-malignant conditions.

Furthermore, to be Aboriginal, from a culturally or linguistically diverse background, elderly, living in a rural or remote area, or from a socio-economically disadvantaged background reduce one's chance of receiving improved quality of life through the principles and practice of palliative care.¹

As such, it can be concluded a significant proportion of people who require access to specialist palliative and end-of-life care do not receive it. This potentially results in unnecessary pain and suffering at the end of life which has implications not only for the patient, but also their families, carers and communities.

This edition examines the causes of inequitable access in five key areas: income, location, social or cultural background, age, and diagnosis or prognosis.

Contributors from across the health sector have identified some of the reasons people do not receive access to needs-based care at the end of life, and propose strategies to guide policy debate to deliver on the promise of quality care at the end of life for all.

Contributors include: John Glover, Sue Hanson, Professor Ken Hillman, Dr Jenny May, Stephen Connor, Deborah Prior, Demos Krouskos, Dr Jenny Hynson, Laurann Yen, Robert Wells, Carol Birks, Victor McConvey, Norman Marshall.

EoL will be launched at *Together! 2009*. It will be available for download from the [PCA website](http://www.pca.org.au) under the publications tab.

B McNamara, L Rosenwax, C D'Arcy Holman, E Nightingale, *Who receives specialist palliative care in Western Australia – and who misses out*, 2004, University of Western Australia, Perth.



PCA member organisation updates

Palliative Care Australia's membership comprises the eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. These organisations created and share the vision, mission and aims of Palliative Care Australia and operate through a federated governance structure.

Together, the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.

Palliative Care Council of South Australia

Retirement of Robyn Rouvray

The Palliative Care Council of South Australia regrets to announce the retirement of Robyn Rouvray from her position as executive officer of the council. We extend to Robyn our very best wishes for her retirement and sincerely thank her for her years of hard work with the council, firstly as project officer and subsequently as executive officer. Although we are already missing Robyn's wisdom and guidance, it is business as usual at the PCCSA office, so please give Sally or Leanne a call if you have any queries.



Dying to know forum

The council hosted a free public forum, 'Dying to know: how to maintain control of your medical care at the end of life', on 25 August to raise awareness about palliative care and to prompt the community to think about planning for the future, through both advance care planning and funeral planning. Those attending contributed to a vibrant

discussion on a wide range of topics. We hope this was only the first of similar forums the council will host.

Palliative Care Queensland PCQ Biennial State Conference Ipswich 2010

Palliative Care Queensland is proud to advise that the 2010 state conference will take place at the Metro Hotel Ipswich International on Saturday 22 May during National Palliative Care Week. A pre-conference workshop will also be held by Ipswich Hospice on Friday 21 May.



The theme of the conference and workshop is 'Looking in, looking out', with a focus on both self care and care of the palliative care community. Guest speakers will include Donna Daniell, CEO Palliative Care Australia, Kevin Larkins, CEO Palliative Care Victoria and Professor Patsy Yates, Director Centre for Palliative Care Research and Education.

For more information, visit www.palliativecareqld.org.au.

Sector news

PEPA

The Program of Experience in the Palliative Approach provides highly flexible, experiential clinical learning experiences for health professionals from a wide range of disciplines, and demonstrates positive outcomes in terms of improved knowledge and abilities of health professionals in providing a palliative approach to care.

Supervised clinical placements within a multidisciplinary palliative care team are between 2-5 days and are provided free of charge with some backfill payments and travel allowances available. The program also offers a range of post-placement support and implementation initiatives.

To apply for a PEPA placement or to find out more about upcoming interactive workshops or post-placement support activities please visit www.pepaeducation.com. Applicants from regional, remote and metropolitan areas are encouraged.



Conferences and events

1st International Conference on Health Services Delivery Management

14-16 October 2009

Phitsanulok Thailand

Theme: strengthening the management of primary health care and district rural health services

Australian presenters will speak alongside international presenters

Contact: Dr. David Briggs dbriggs@une.edu.au

Dr P. Taytiwat taytiwat@yahoo.com

Carolyn Marsh cmash@achse.org.au

The Rural Medicine Australia 2009 Conference

29 October - 1 November 2009

Melbourne

Jointly hosted by the Australian College of Rural and Remote Medicine and the Rural Doctors Association of Australia

www.acrrm.com.au

Looking in, looking out

Palliative Care Queensland Biennial State Conference

22 May 2010

Ipswich

www.palliativecareqld.org.au

PCA - responsibilities of office bearers

Election of office bearers

In accordance with the PCA Constitution, the position of president elect will be elected at the 2009 PCA Annual General Meeting on Tuesday 17 November 2009.

Term

Office bearers are elected for a two year term at alternate annual general meetings. Each office bearer, unless they sooner resign their office, holds office until their successor is elected at the next alternate annual general meeting.

A retiring president is eligible for re-election but no person is permitted to hold this office for more than two successive terms of two years. A retiring vice president, secretary, treasurer or general member is eligible for re-election, but no person shall hold any of these offices for more than three successive terms of two years.

Role and responsibilities

Governance of Palliative Care Australia, subject to the rules of the PCA Constitution, is vested in the Executive Board, which is comprised of:

- president
- vice president
- Secretary
- Treasurer
- general member
- immediate past president or president elect, or if these offices are both vacant, a second general member.

The primary role of the Executive Board is one of trusteeship on behalf of its members, ensuring that the organisation remains viable and effective in the present and into the future.

The Executive Board is accountable for all PCA organisational and strategic matters. All decisions are made collectively by the Executive Board and all board members share equal responsibility for those decisions.

Executive Board members act in the best interests of Palliative Care Australia, not for personal interest or in the nominating member's interest. Matters discussed during Executive Board meetings remain 'commercial in confidence', unless otherwise agreed.

Executive Board members meet by teleconference up to once per month, for approximately two hours, and face-to-face at least once per year to discuss PCA's strategic direction, financial position, policies and other matters of importance. Papers for meetings are distributed electronically beforehand for members to prepare.

President elect

The position of president elect is a key element of PCA's succession planning arrangements to ensure seamless transition between presidential leadership.

What does an executive board position offer?

The position offers the opportunity to share in the decision making of a dynamic peak national health organisation, being exposed to new and different issues, working in a collaborative and challenging environment, representing PCA in different fora, and sharing in the achievements of PCA.

Selection of nominees

The Executive Board requires a mix of skills and experience to work as a well-rounded team, to govern PCA both now and into the future. Some core skills that should be represented on the Executive Board that are not unique to PCA but required by all organisations include:

- **strategic expertise** – the ability to review strategy through constructive questioning and suggestion
- **organisations expertise** – the ability to establish policy framework, and review and monitor organisational performance
- **accounting and finance** – the ability to read and comprehend organisational accounts, financial material presented to the Executive Board, financial reporting requirements, with some understanding of the wider financial environment
- **managing risks** – experience in managing areas of major risk
- **members and stakeholders** – the ability to understand and relate to members and stakeholders
- **palliative care** – knowledge and experience.



**Palliative
Care
Australia**

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life.

Specialist palliative care providers have specialist knowledge, skills and expertise in the care of patients, their families, carers and communities, who are living with and dying from a terminal condition.

Quality care at the end of life is realised when strong

networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community - working together to meet the needs of all people.

PCA vision - quality care at the end of life for all.

PCA mission - to influence, foster and promote the delivery of quality care at the end of life for all.

Palliative Care Australia

Suite 4 | 37 Geils Court | Deakin ACT 2600 PO Box 24 | Deakin West | ACT 2602
 t: +61 2 6232 4433 f: +61 2 6232 4434 e: pcainc@palliativecare.org.au

NSW	Palliative Care New South Wales PO Box M48 Missenden Road NSW 2050	t: +61 2 9206 2094 / 0403 669 491 f: +61 2 9206 2094 w: www.palliativecarenewsw.org.au e: info@palliativecarenewsw.org.au
QLD	Palliative Care Queensland PO Box 437 Virginia QLD 4014	t: +61 7 3633 0096 f: +61 7 3633 0086 w: www.palliativecareqld.org.au e: enquiries@palliativecareqld.org.au
VIC	Palliative Care Victoria Suite 3C, Level 2, 182 Victoria Parade East Melbourne VIC 3002	t: +61 3 9662 9644 f: +61 3 9662 9722 w: www.pallcarevic.asn.au e: info@pallcarevic.asn.au
WA	Palliative Care WA 15 Bedbrook Place Shenton Park WA 6008	t: +61 8 9382 9367 / 1300 551 704 f: 1300 551 704 w: www.palliativecarewa.asn.au e: pcwainc@palliativecareswa.asn.au
SA	Palliative Care Council of South Australia 202 Greenhill Road Eastwood SA 5063	t: +61 8 8291 4137 f: +61 8 8291 4122 w: www.pallcare.asn.au e: pallcare@pallcare.asn.au
TAS	Tasmanian Association for Hospice and Palliative Care PO Box 834 Kingston TAS 7050	t: +61 3 6285 2514 f: +61 3 6239 6030 w: www.tas.palliativecare.org.au e: tahpc@intrepidonline.com.au
ACT	ACT Palliative Care Society PO Box 88 Civic Square ACT 2608	t: +61 2 6273 9606 f: +61 2 6273 9590 w: www.pallcareact.org.au e: office@pallcareact.org.au
NT	Palliative Care Northern Territory PO Box 42255 Casuarina NT 0811	t: +61 8 8922 6769 w: www.nt.palliativecare.org.au e: pcnt@palliativecare.org.au
ANZSPM	Australian and New Zealand Society of Palliative Medicine PO Box 238 Braidwood NSW 2622	t: 0458 203 229 f: +61 3 8677 7619 w: www.anzspm.org.au e: karen@anzspm.org.au