

Delivering patient choice

Better living conditions and health care have led to increased longevity. Rapid technological development has allowed people who would previously have died to be kept alive for longer periods of time.

However, these very successes have led to practical, legal and ethical issues around end-of-life care and extending the dying process and raised questions as to whether the health system is equipped to deliver care according to patient choice.

Research in Queensland with carers of people who had died the previous year revealed many stories:

- 'My father was left hooked up to machines until the very end. We couldn't even get close enough to give him a hug and say goodbye.'
- 'Mum always said she wouldn't want to be resuscitated if her heart stopped, but they wouldn't listen.'
- (Competent man in his late 80s with multiple problems voluntarily chose to stop eating and drinking.) 'First of all he was stubborn when he was in hospital; he wouldn't eat, he was just starving himself ... so they had to force feed him. They put a tube down his nose and then they had to tie him in the bed because he kept pulling it out. He just didn't want it.'

That is assault. Being in hospital does not negate the right to informed consent – the health system must be organised to provide and deliver care according to patient choice.

Many problems stem from confusion over what is, or is not, euthanasia. Some commonly-held, erroneous beliefs are that euthanasia includes:

- giving increasing amounts of needed pain relief which may also shorten the person's life

(continued p.3)

From the president

With the disruption of a federal election now largely behind us, it is timely to turn our minds again to the substance of health reform. Each year, around 140,000 people in Australia die – for around seventy-five percent of these people, death might have been expected or anticipated.

How is the health system performing for these people – is it delivering the right care at the right time in the right place? In spite of the dedication and professionalism of all who work in the health sector – the system is not delivering consistently for all Australians.

The National EoL Framework Forum, under the auspices of Palliative Care Australia, recently released [Health system reform and care at the end of life: A guidance document](#). This seminal document represents the work of the forum – comprised of professionals across the health sector with an interest and expertise in quality care at the end



of life. The document was developed to assist policy makers, planners, and service providers navigate their way through and interpret reforms with the specific aim of improving end-of-life care. I highly recommend the document for reading and am sure you will find it informative and proactive.

Realising quality care at the end of life for all Australians will require fundamental structural change within the health system. This requires a commitment over the long-term, to cooperation between governments, health professionals and consumers – working together to reform the health system.

Professor Margaret O'Connor AM
President



In this issue

PCA update	2
Policy report	
Health reform agenda	
Advance care planning	
PC inquiry	
Position statements	
NSAP	
Recruitment update	
Peer mentor visits	
Feedback to NSAP	
PCA Board elections	4
11 th APCC conference	4
News brief	4
Sector news	5
PEPA	
CareSearch	
Information and resources	5
PCAMO updates	6
Palliative Care Queensland	
Palliative Care Victoria	
Conferences and events	6

Palliative Care Australia - update

Policy report

The health reform agenda

At the time of writing, Australians are heading into challenging but exciting waters uncharted at a federal level since 1940 – a ‘hung’ Parliament.

In health, Australians have had grand plans and promises over the last three years which so far have delivered little. What the current deadlock does offer us is the prospect that perhaps a government can be negotiated with a firm commitment to genuine reform in health and other areas.

At a national level, PCA will be taking up offers of ‘post-election’ meetings with both the health minister and shadow health minister, and will be seeking to draw on the links we have established with at least two of the key independent MPs and the Greens, in an endeavour to put genuine health reform onto the agenda for the new government.

From PCA’s perspective, of course, ‘genuine health reform’ involves a more integrated health system in which people with terminal conditions can move seamlessly between the types of services they need to access. Any influence you or your organisations may have with your local MPs, senators, or parties may be helpful in this regard.

Advance care planning

Palliative Care Australia has been advocating the concept of advance care planning for some years. In March 2008, the Australian Health Ministers’ Advisory Council (AHMAC), consisting of the heads of the health departments of all state and territory governments, asked its Clinical, Technical and Ethical Principal Committee (CTEPC) to progress the development of nationally-consistent guidelines for advance care directives (ACDs).

To progress this, the CTEPC established a National Advance Care Directives Working Group (NACDWG) which has prepared the draft *National advance care directives framework* and the *Consultation companion guide*.

Because PCA has been influential in encouraging health ministers to consider how ACDs were viewed nationally, representatives from the NACDWG are meeting with PCA as part of a targeted national consultation process. This process will refine the draft framework before the document is presented again for the consideration and endorsement of ministers.

This is an important step to develop nationally-consistent mechanisms that respect the rights of people to have a say about future care which will be provided when their capacity to make decisions is impaired or lost. It also fits with norms of informed consent and clinical practice within Australian health and aged care settings.

Productivity Commission inquiry

The PCA submission to the Productivity Commission’s Inquiry into Caring for Older Australians is number 77 on the Productivity Commission’s website at www.pc.gov.au.

As reported last month, this is an important opportunity to consider issues currently impacting on the vital interrelationship between palliative care and the aged care system, and on improving access to optimal end-of-life care for all elderly Australians.

Palliative Care Australia has met with key Productivity Commission officials, and has been invited to participate in two national round-table consultations, one on workforce, and one on care.

Policy opportunity with AMA

We have met with members of the AMA Federal Secretariat’s policy team to discuss working together (and with other players) on workforce issues involved in the health reform agenda, and particularly on better incorporating palliative care needs.

Dr Rod McRae, Chair of the AMA Federal Council (and a member of the AMA Federal Executive) is a member of the national forum which developed our [Health system reform and care at the end of life: A guidance document](#). The AMA Federal Committee on Health and Aged Care is considering the guidance document at its next meeting. We are hopeful an outcome will be some collaborative work around the place of palliative care in the new networks (both hospital and Medicare locals), including referral pathways criteria, and funding.

Review of PCA policy position statements

Palliative Care Australia is commencing a review of our current policy position statements to assess their effectiveness and appropriateness. Our position statements can be found at www.palliativecare.org.au. Any comments would be gratefully received – bruce@palliativecare.org.au.

Standards – NSAP

The new NSAP team is forging ahead and wishes to thank everyone for their patience as we settle in to our new roles. We are now in a great position to continue supporting services as they prepare for self-assessment, complete self-assessment, or implement their action plans.

We are reviewing our database to identify where specialist palliative care services across Australia are in their progression with NSAP. An NSAP team member will be contacting you in coming months to confirm this information and offer whatever support is required for your service. Importantly, we are analysing the activities services have reported on as key areas for improvement. As a

consequence, we will be developing key areas of focus and providing professional development support for all services through collaborative improvement workshops. So – watch this space!

Recruitment update

Victoria

Services across Victoria commenced self-assessment in late June. These services are well into their self-assessments and are doing really well. The team looks forward to supporting these services through to their report submission and into their action plan implementations. If you are currently reporting in Victoria and have any queries at all, please do not hesitate to contact us.

Western Australia

Services in Western Australia are progressing well with some commencing self-assessment and others continuing to prepare for self-assessment. Should you still need to sign-up for NSAP in Western Australia contact the NSAP team on 02 6163 8419.

South Australia

Some services in South Australia have commenced self-assessment and are doing extremely well. The full state roll-out to South Australia is scheduled to occur from 20 September with a workshop in Adelaide. We will be holding a short meeting prior to 20 September to ensure services have their paperwork in order to commence self-assessment in late September and report before Christmas.

New South Wales and Queensland

Roll-out in these states occurred several months ago and significant activity continues within each state. Should you still need to sign-up for NSAP in NSW or Qld contact the NSAP team on 02 6163 8419.

Peer mentor visits

Each participating service is invited to participate in the NSAP peer mentor process, approximately six months after submission of their self-assessment report. The purpose of the peer mentor process is to validate the self-assessment undertaken by a service. It is not an independent review and assessment process.

Peer mentorship gives services the perspective of an experienced palliative care practitioner from outside their service who acts in a mentor role for the service. The peer mentor will be an industry leader.

Mentor-based peer support is based on the principles of mentoring. It is:

- the process of checking, critiquing and improving practice
- based on the willingness of services to open their practice to the scrutiny of experts in the field
- focused on achieving improvement.

It has the confidence of participants because it sets out to check, critique and improve –



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(continued from p. 1)

- respecting a patient's right to refuse further treatment
- withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient.

None of these is euthanasia. The first is often referred to as 'the doctrine of double effect' where the primary intention is to relieve pain but a secondary, unintentional effect, may be the hastening of the person's death by a few hours or days. This is accepted by most religious and medical groups, including those who strongly oppose euthanasia.

The second is a legal and moral right possessed by every competent person, both under common law and statute law, relating to assault.

The third is good medical practice. Often the treatment is not prolonging life, it is merely prolonging the dying process. Futility is generally agreed to be when, from the patient's viewpoint, burden outweighs benefits.

Witnessing poor deaths has increased fear in the general community about the end stage of life. Research has found the majority of community members were afraid (in ranked order) of loss of mental faculties, loss of control, loss of independence, being a burden on family, and loss of dignity, ahead of fear of physical pain. In every study, fear of death itself was rated last. People were not afraid of dying, they were afraid of the dying process.

One option to help address these fears is advance care planning (ACP). Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, ACP helps ensure that if a patient loses capacity, their treatment decisions are respected.

Every state and territory in Australia has legislation relating to the appointment of a substitute decision maker and all except New South Wales and Tasmania have specific legislation making advanced health care directives (AHCDs) or equivalent, legally binding on health professionals. New South Wales and Tasmania rely on the common law for enforcement of this principle, recently confirmed by a decision in the NSW Supreme Court. The AHCD takes precedence over the substitute decision maker.

Systems changes are also required to make completion of AHCD and the appointment of substitute decision makers a routine part of general practice and to change admission forms in hospitals and residential aged care facilities to record if a person has an AHCD or substitute decision maker, with an alert placed on the patient's file and in the computer.

Colleen Cartwright - Professor of Aged Services - Southern Cross University

This is an abridged version of an article published in the Winter 2010 edition of *EoL – Towards quality care at the end of life*. For the full version, including references, see www.palliativecare.org.au.

not judge. Peer mentorship is an important, although not compulsory, component of NSAP.

How can I get more information?

Section 8 of the National Standards Assessment Program Guide provides information on the NSAP peer mentor component.

Should you wish to discuss peer mentorship and its role in your service with a member of the NSAP team - call the team on 02 6163 8419.

Feedback for the NSAP Team

Please feel free to call or email if you have any thoughts or comments regarding NSAP. We are always keen to hear feedback to ensure our ongoing quality improvement within the program.

Have you been unable to commence NSAP?

If specialist palliative care services in your state have already begun NSAP but your service has not, you are still able to sign-up to undertake the NSAP self-assessment. Services in Western Australia, New South Wales, Queensland, Victoria, Tasmania, and the Australian Capital Territory can sign up now and register to commence NSAP at any time.

If you have not yet signed up, contact the NSAP team to discuss options for beginning NSAP at a time that suits your service.

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

11th APCC conference

Diversity - Strengthening quality care at the end of life

The 11th Australian Palliative Care Conference will be held at the Cairns Convention Centre, Queensland from 30 August to 2 September 2011. Looking at diversity in people, health, and care, the conference provides an opportunity for all who have an interest in quality care at the end of life to come together and share their knowledge, experience, ideas and research.

Conference chair Dr Scott Blackwell said 'Diversity 2011 is shaping up to be a great conference. I can guarantee there will be something in the program for everyone.'

The conference website will be up and running at www.austpalliativecareconference.org.au in early September. The site will contain all the information you need to know about the conference.

The call for abstracts will open towards the end of 2010 and early bird registrations will be available from early 2011.



Spring is the perfect time to visit tropical north Queensland, and with the conference finishing on a Friday, you can stay on for the weekend and explore this beautiful part of the world.

We'll be updating you regularly with information about Diversity 2011 as it comes to hand. This conference will be the highlight of the palliative care calendar in Australia in 2011. We look forward to seeing you there!

News brief

Ageing in Victoria

The Victorian government has recently released the *Ageing in Victoria Framework* which outlines a whole-of-government approach to caring for older Victorians. The framework is focused in three areas: good health and wellbeing, age-friendly communities, and economic and social participation. The framework is available at www.seniors.vic.gov.au.

Chaplaincy and pastoral care in NSW

The New South Wales Department of Health has recently signed a memorandum of understanding with the Civil Chaplaincies Advisory Committee NSW – recognising the important work chaplains do in hospitals and healthcare institutions, supporting patients and families.

Director-General, Professor Debora Picone stated NSW Health 'recognises that patients, their families and staff who work in public hospitals and healthcare institutions have a basic right to spiritual care and should be able to access chaplaincy and pastoral care services when they need to, no matter what their background or faith may be'.

For more information, see www.health.gov.au.

PCA Board elections

Consider running for the PCA Board.

At the 2010 Annual General Meeting on Thursday 28 October, elections for several PCA board positions will be held. The positions to be elected are:

- vice-president
- treasurer
- secretary
- general member.

Nominees must:

- be current members of a PCA member organisation
- be nominated by two current members of a PCA member organisation.

More information including the nomination form is available at www.palliativecare.org.au.

Sector news

Program of Experience in the Palliative Approach (PEPA)

The 2010-2011 phase of PEPA is officially underway, with workforce placements of 2-5 days within a multidisciplinary palliative care team available for primary health care practitioners from all disciplines.

In addition to undertaking a supervised clinical placement, participants are supported to integrate learning into practice and invited to participate in post-placement support activities. Examples of workplace activities that have been implemented to date include:

- workplace tool development and/or improvement, with the outcome of improved care planning and implementation, early identification of the deteriorating resident, a more holistic approach to care provision, and greater efficiency through intentionally streamlining the approach to care
- in-service training provided to staff
- more effective assessment and monitoring of pain
- modelling to other staff of improved communication techniques with families and residents including provision of information that leads to informed choices and managing their expectations with greater awareness
- provision of feedback to the regional palliative care team regarding staffing, resource allocation, assessments, and outcome measures as observed within a larger metropolitan service.

To apply for a PEPA supervised clinical placement or to find out more about experiential workshops and ongoing post placement support, visit www.pepaeducation.com. Applicants from various disciplines and regional, remote, and metropolitan areas in all states and territories are encouraged to apply.



CareSearch

Introducing the Nurses Hub

A new resource to support palliative care nursing has been introduced to the CareSearch website. The [Nurses Hub](#) brings together evidence-based information and quality resources to help specialist palliative nurses find specific information on patient care issues, and stay up to date with new therapies and approaches. The Hub has a number of sections including:

- [clinical](#)
- [areas of practice](#)
- [research](#)
- [education](#)
- [nurses providing palliative care](#)
- [policy quality standards](#)
- [resources](#)
- [nurses news](#).

Each of these sections provides information, links to tools and resources, and further references. Related CareSearch

pages are highlighted and a free full-text article can be read immediately or downloaded and printed.

Nurses can also register to receive the monthly newsletter, [nurses\[HUB\]news](#), to keep them up to date with what's happening in palliative care and what's new on CareSearch and in the Nurses Hub.

The Nurses Hub [poster](#) and [information sheet](#) can be printed and displayed or distributed to nursing staff.

Good quality information and resources are now available to support the nursing staff caring for palliative patients. The [Nurses Hub](#) is free to use and available now at www.caresearch.com.au.

For further information about the Nurses Hub or to order CareSearch promotional materials, contact Natasha Schembri on 08 7221 8227 or by email Natasha.Schembri@flinders.edu.au.



Information and resources

Dying with dignity forum

On 3 August, Radio National's *Australia Talks* program held a forum, Dying with dignity. Panel members included PCA's President Elect, Dr Scott Blackwell, Dr Philip Nitschke, Associate Professor Patrick McArdle from the Australian Catholic University, and Dr Kaarin Anstey, Director of the Ageing Research Unit at the Australian National University.

A lively panel discussion was followed by questions from participants. If you missed the program, you can listen to it at www.abc.net.au.

Volunteer opportunities in China

Chinakidz has recently opened a small palliative care unit in Changsha, Henan province. The unit cares for children who have been assessed by orphanage doctors and deemed to have a life expectancy of six months or less.

There is limited formal training in palliative care in China, and the organisation is in the process of developing its own course. Chinakidz is seeking volunteers to share their knowledge and experience. For more information, see www.chinakidz.org.

World Hospice and Palliative Care Day

The theme 2010 is 'sharing the care', highlighting the role of partnerships to support care for people living with a terminal illness.

The day, on 9 October, aims to highlight how good working partnerships between service providers, governments, hospitals, patients, carers, and communities are vital to the provision of quality care. For more information, see www.worldday.org.

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 Queensland

Relocation

Palliative Care Queensland has relocated to its new premises in the Maurice Blackburn Tower, Brisbane CBD. Our new contact details will be:

Palliative Care Queensland
Level 1
193 North Quay
Brisbane 4000

PO Box 437
Virginia Qld 4014

t: 07 3211 2299
f: 07 3211 1175

We apologise for any inconvenience caused during the relocation period. For more information, see www.palliativecareqld.org.au.



Palliative Care Victoria

Evaluation of the Victorian Palliative Care Volunteer Training Resource Kit

In December 2007, the Helen Macpherson Smith Trust provided Palliative Care Victoria (PCV) with funds for the development of the *Victorian Palliative Care Volunteer Training Resource Kit* (VTRK).

This project aimed to ensure consistent best practice palliative care volunteer training across all inpatient and community palliative care services in Victoria. This kit contained:

- a competency based Palliative Care Volunteer Training Manual - Facilitator's Guide
- a Learner's Guide
- the current Victorian Palliative Care Volunteer Standards (DHS 2007).

This kit was provided to all Victorian palliative care volunteer services and has been purchased by many palliative care volunteer services across Australia. In Victoria some aged care services are now taking this up to assist in training. International interest has seen this kit used in New Zealand, Spain, Canada, and the UK.

A formal evaluation of the kit will be undertaken shortly to ascertain how well the product is meeting user group needs, and what further development is required. If you have purchased this kit you may be contacted by the project officer over the coming months to provide comment.

For more information contact Palliative Care Victoria at info@pallcarevic.asn.au or t: 03 9662 9644.

Palliative Care
V I C T O R I A

Conferences and events

Ars moriendi – Palliative medicine in the 21st century

Australian and New Zealand Society of Palliative Medicine
14-17 September 2010
Adelaide
w: www.anzspm.org.au

Hospice and palliative care in the global community

22-25 September 2010
Fresno, California
w: www.hindshospice.org

Hands on in the Hunter: Innovation, inclusiveness, and integration

Palliative Care NSW biennial state conference
3-5 November 2010
Hunter Valley
w: www.palliativecarensww.org.au

2nd International conference on public health and palliative care

Bangabandhu Sheikh Mujib Medical University (Bangladesh),
Institute of Palliative Medicine, Kerala (India), University of
Bath (UK)
21 – 23 January 2011
Dhaka, Bangladesh
Abstracts open on all aspects of public health approaches to
palliative care
Closing date for abstracts: 15 October 2010
w: www.pubhealthpallcare.in

Rural and remote Australia: The heart of a healthy nation—11th National Rural Health Conference

13-16 March 2011
Perth
Call for abstracts now open
w: www.ruralhealth.org.au

Have something for the e-bulletin?

PCA invites contributions from readers seeking to promote their activities in the palliative care sector.
Contact: e: editor@palliativecare.org.au or t: 02 6232 4433.

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 3211 2299 / 1800 660 055 f: +61 7 3211 1175 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 4489 Alice Springs NT 0811	t: +61 8 8951 6762 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

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