



PCT NEWS

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**To contact any of our Councillors please email
secretary@tahpc.org.au**

From the President

Since before Christmas the General Manager and I have met with the State Minister for Health, Federal Government and Opposition Members, the Federal Minister for Health's advisors, as well as Senators and their advisors. We have been working hard to inform them about the fantastic work we have achieved under the Better Access to Palliative Care in Tasmania (BAPC) Program and the impact on the community if this work is not continued.

Our funding, from the Australian Government, nominally expired on 30 June this year but we have negotiated an extension to 30 September 2016.

We have received constructive responses from each major party and it is our intention to follow up on these once the outcome of the Federal election is known.

Dale Eastley – PCT President

Association adopts new trading name

The last newsletter explained that the Tasmanian Association for Hospice and Palliative Care Inc. was intending to register and use a Trading Name, Palliative Care Tasmania. This has happened. It has generally been well received. Using Palliative Care Tasmania as the trading name does not alter our registered name with the Australian Securities Investment Commission (ASIC).

In making this decision to use Palliative Care Tasmania as the trading name, ie the name by which the organisation will be generally known, the Council was mindful that the national body is known as Palliative Care Australia and the other states use the same approach that we have now adopted.

This year's membership renewal notice and application for membership will reflect the change in the name that is used for operational purposes. If you would like any clarification of this issue please contact Dale Eastley on president@tahpc.org.au



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From the General Manager's Desk

The team has been working hard across Tasmania to deliver the Better Access to Palliative Care in Tasmania program. Over the last 18 months we have provided education and information to 13,000 people. We have provided community grants to 72 community organisations facilitating over \$1 million in projects. We have also provided education to about 1,400 medical professionals.

We have recently completed our Training Outcomes Evaluation which is showing us that over three quarters of people who attended our education have recommended our training to other people and that the vast majority have taken what they have learnt and used it in their workplaces or communities. The most popular education this financial year has been grief and bereavement, closely followed by palliative care. The majority of respondents want more education in these areas and also death literacy.

In the period from 1 July to 30 September we will be delivering education around the State called I Don't Know What to Say. This covers grief and loss, palliative care, death literacy and communication. Please see our website www.tas.palliativecare.org.au for more information about these events and how you can attend.

Colleen Johnstone - General Manager

HAVE YOU BEEN TO THE TAS PALLIATIVE CARE FB PAGE YET?



The best way to keep up to date with what's happening at Palliative Care Tasmania is to check into our Face Book Page

'Like' Our Page and

see what we're up to!

Go to <https://www.facebook.com/TasPalliativeCare>

Palliative Care Tasmania membership goes online

This year sees Palliative Care Tasmania take a brave leap into the 21st Century World of online membership!

From now on the preferred method of renewing or joining PCT will be via the membership function on our website and we are asking all members to renew and pay in this way.

The first time you renew on the web it will be like joining as a new member, as you will need to complete the form and give all of your details, including your postal address.

Payment is by credit card or PayPal, *NOTE: You do not need to have a PayPal account to pay by credit card on the website.*

If you don't have access to the internet and you want to pay by credit card, or you are unsure about joining on the Web, you can call Christina at the office on 6231 2799 and she will register you on the website while you are on the phone.

If you want to pay by cheque, send it with the renewal notice to our new PO Box 3060, West Hobart 7000 and we will manually register you on the website.

If you took advantage of the Expo renewal offer and have already paid your membership for the coming year, we will add your details to the website database for you and you can happily ignore any renewal notices until this time next year.

To renew your membership go to www.tas.palliativecare.org.au/membership and click on membership in the menu. *(If you happen to have any issues with the link displayed in the renewal notice that you have received, then please note that this one will work).*

**Christina Bosly-Pask, Administration &
Events Coordinator**



North and North West Happenings

The past month has been a busy one with the Dying to Talk Expos finally coming to fruition after many months of planning, a trip to Flinders Island and planning future education events.

The Dying to Talk Expos were a great success, with the Albert hall in Launceston having 40 exhibitors who saw an estimated 480 members of the community come through the doors.

City Park Radio broadcast from the site, and the MADE installation and Interweave arts were great examples of how to promote death literacy through the arts. The hot coffee and snacks that were available for a gold coin donation were greatly appreciated on the cold, crisp but beautiful day.

We received 130 feedback forms which were overwhelmingly positive. People felt they gained a much better understanding of services in the north, they were encouraged by the friendliness and helping nature of the exhibitors and felt better informed about what they should consider at end of life. The MADE installation was considered to be a wonderful way to showcase how precious life is.

And of course we can't talk about the expos without thanking all of the volunteers who helped to make it such a great event.

I was asked by Flinders Island Council to provide information sessions on Advance Care Planning (ACP) at the Island's Multi-Purpose Centre. As I had not been to Flinders with PCT before I was unsure of what the response would be or who would turn up. To my pleasant surprise I had members of the public and Health Service Providers attend each session, with a total of 15 attending. This a great turn out. The sessions went well and I have been invited back and will be providing a session on Grief & Loss for the community and another ACP for the Aboriginal craft group who gather on Wednesdays at FIAAI. I was lucky to be on Flinders Island on such a still sunny day and encourage those who have never been to visit, the friendliness of the locals has to be experienced to be believed. I even got to meet and cuddle Derek the wombat. Well worth the trip.

Jenny Fuller and I are in the final planning stages of putting together a state education tour to areas that have not been serviced by PCT over the past 6

months. The talks are based around communication at end of life and are aptly named "what to say, when you don't know what to say". The feedback from education sessions often shows that people want to know more about communication and what to say. These talks discuss that and aim to assist those supporting people living with life-limiting illness, their carers and people who are grieving.

Sharon King - Northern Project Manager

July-September Education Calendar

Date	Location	Topic
Wed 20 July	Somerset	"I Don't Know What to Say" Communication in palliative care and grief and loss
Thur 21 July	Smithton	
Mon 25	Devonport	
Tues 26	Devonport	
Tues 26	Oatlands	Palliative Care Basics
Thur 28	Ulverstone	"I Don't Know What to Say" Communication in palliative care and grief and loss
Thur 4 August	Hobart	Peer Educator in Advance Care Planning refresher
Mon 8	St Helens	"I Don't Know What to Say" Communication in palliative care and grief and loss
Tues 9	St Marys	
Wed 10	Bicheno	
Thur 11	Swansea	Advance Care Planning
Fri 12	Orford	"I Don't Know What to Say" Communication in palliative care and grief and loss
Tues 23	Launceston	Peer Educator in Advance Care Planning refresher
Wed 24	Flinders Island	
5 - 9 Sept	West Coast	Venues and topics to be confirmed

Go to www.tas.palliativecare.org.au for more details of venues and registration.



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Australian Grief & Bereavement Conference – May 2016

I was very grateful to have the opportunity to attend the national conference in Melbourne, where we were treated to the wisdom and experience of many of the 'elders' of bereavement research and practice. Prof Colin Murray-Parkes, (now in his 89th year), reflected on his belief that attachment theory still has relevance in relation to how we respond to death, abuse, trauma. Dr Sandra Bertman discussed her own practice and research using evocative images to encourage people to reflect in writing on their experiences of grief. Many profound responses were elicited by this method, which is clearly effective for people able to express themselves through the written word. Dr Robert Neimeyer is well known for his many years working in the area of meaning-making in mourning. He described the current research programs being undertaken by incredible research networks with teams all around the world. Dr Edward Rynearson described his research with people whose grief is in response to traumatic, violent death and the validity of Restorative Retelling Narrative Therapy, finding that fixation on the circumstances of the death is decreased through skilled use of the therapy.

A particularly interesting presentation was given by Dr Andy Ho, describing 'Dignity conserving end of life care for people living in aged care facilities in Hong Kong'. The demographics faced in HK are challenging – there has been an 85% growth in the population over 65 in the past 20 years. 6.8% of the population live in long term residential care. A dignity program was researched to enhance the psycho-social, spiritual, maintaining family connections, quality of life and personal autonomy of residents, leading to improved well-being of residents, with increased sense of hope, spiritual peace, improved relationships, and an increase in will to live rather than a wish to die. Changes in attitude by both family and staff who all understood the family as a 'partner' in care rather than merely a 'recipient' of care by others were also observed.

Another innovation was to have an annual field work attachment for executive management level staff who were otherwise removed from the daily realities of care and residence in institutional settings.

One of the most curious presentations was 'Sharing Grief with the dead after a devastating Tsunami'. This research was carried out by the Tohoku Gakuin University in response to social and print media reports from taxi drivers in the areas near the earthquake and tsunami of 2011 that they had carried 'ghost passengers'. The researchers found that the drivers were mostly locals with strong attachments and connections in the devastated communities. They had also experienced the death of relatives and friends, and were witnessing first-hand the devastation wrought on their community on a daily basis. After being initially disturbed and frightened by the experience of seeing a passenger in the taxi who interacted with the driver, and then simply disappeared as they travelled along, the drivers later reflected that they cherished the encounters. The Japanese spiritual beliefs around death hold strong ongoing bonds with the deceased ancestors through Buddhist practices.

The researchers believe that the taxi driver stories help the community to feel continuing connection with the people lost in the earthquake and tsunami, and bind the community together in mutual loss and connection.

Reminder: the Australian Centre for Grief and Bereavement produces some great resources – fact sheets, videos, on-line support – useful things for service providers as well as people who are grieving, or who just want more information. Go to www.grief.org.au

Jenny Fuller:
Education & Community Facilitator



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National Palliative Care Week

National Palliative Care Week was a busy week this year for Palliative Care Tasmania. We started the week on Saturday 21 May in Launceston at the *Dying to Talk Expo*. We had 40 exhibitors from the palliative and end of life care sector providing information to the Northern Tasmanian community about services. The event was held at the Albert Hall and about 480 Northern Tasmanians attended during the six hours of the expo. The vast majority of attendees were surprised at the scope of services available. Two of the most frequently visited exhibitors were Calvary's Melwood Unit stall and the Specialist Palliative Care Service – North stall. Attendees reported that they were impressed with the scope of care provided by Melwood and SPCS and were surprised that Melwood was not limited to four public beds but had, the week of the expo, 10 public patients in the Unit.

A week later we rolled the Expo to Hobart's Princes Wharf No 1 Shed. This time we had just over 50 exhibitors and over 800 people attended during the six hours the Expo was open. We were fortunate to have Liz Callaghan, PCA CEO, attend the event. Liz remarks how impressed she was with the way the end of life sector in Tasmania could collaborate and work together to deliver such high quality and informative events. Again Expo goers were very impressed with the information provided by the SPCS- South, Calvary's Gibson Unit, and the Hospice@home program. In addition, Unique Timber Coffins and the University of Tasmania's Body Bequest Program seemed to be crowd favourites.



The flags flew high for Tasmania's first Dying to Talk Expo



Jenny goes through the ACD with Launceston Expo visitors

Across both Dying to Talk Expos over 1200 attended. There were groups of teenagers really interested in getting information to help them talk to friends and older relatives about dying, people from diverse cultural backgrounds interested to see what type of care options were available in Tasmania, and older people interested in getting information to help them plan for their own end of life care. In terms of raising awareness, the Expos really achieved this in a big way. It was also a great event that enabled exhibitors to develop new networks and strengthen existing ones.

I would like to thank my team at Palliative Care Tasmania for organising the Expos, it was a massive job but the results speak for themselves. I would also like to particularly thank the team of volunteers we had from The Hobart District Nurses, Hospice Volunteers South, Palliative Care Service North, and Nick Bosly-Pask who was our MC at both events. I'd also like to thank two young volunteers Sophie Onslow (12 years old) and Angus Bayley (9 years old) who did a fantastic job handing out balloons and talking with young people.

During NPCW we also hosted a CEO lunch to provide increase awareness of cross sectoral role palliative care play. We had three guest speakers, Liz Callaghan (PCA), Bruce Rumbold (Latrobe University) and Kerrie Noonan (Groundswell). Guest speakers spoke about the community aspects of palliative care, focusing on the fact the palliative care is everybody's business and is mostly provided in the community by the community. All of the CEO's and community leaders who attended learnt something new and went away with a different perspective of palliative and end of life care.

Colleen Johnstone, General Manager



Guest speaker at the NPCW lunch Kerrie Noonan from Groundswell

PALLIATIVE CARE TASMANIA

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The Financial Costs of Motor Neurone Disease

Colleen and I recently attended a presentation by Deloitte Access Economics (DAE) on the financial costs to both the sufferers, families, and also the health system, for a person with MND.

MND Tasmania had organised the presentation by Lynne Pezzulo from DAE, which took place in the impressive Long Room at Parliament House. Guy Barnett, MP, and supporter of MND Tasmania, introduced the presentation, which was attended by several other MPs, clinicians and business representatives.

Deloitte Access Economics have recently undertaken an economic analysis of the costs of MND which illustrates sharply the enormous impact and burden of MND on families and the general economy: figures such as \$31,500 for aids and equipment per person and combined hospital and home care of \$24,000. The “burden of disease costs” ie suffering, disability and loss of well-being and ability to work, come in at nearly \$2 billion. (All figures rounded and quoted as per annum). It is calculated that 18% of costs are met by the family.

Even more telling is the impact of the burden of care, with the main family carer needing to spend up to 10 hours per day in caring for the person with MND. Not only the person with MND, but also the carer, often have to give up paid work much earlier in their life span than the general population, in order to cope with the demands of the disease. Due to this there is also a big loss to the general economy.

Lynne found herself shocked by the figures for MND in comparison to similar studies she has done with other chronic diseases. This type of study aims to give objective information to policy makers and researchers, when assessing general health costs. There is no known cause or curative treatment for MND and only one medication which relieves some symptoms, so that money for research is needed urgently to further investigate the causes of this very challenging illness.

For more information contact MND Tasmania info@mndatas.asn.au or go to the website at www.mndatas.asn.au.

Source of figures: Deloitte Access Economics – Economic analysis of motor neurone disease in Australia, Nov 2015

Jane Jupe

Strengthening Dementia Services Conference

The COTA Australia Strengthening Dementia Services conference brings together policy makers, peak bodies, leading providers who have successfully tackled the dementia gaps that exist.

Key themes and sessions:

- **National strategy for dementia** – addressing the need for research and policy
- **Making dementia a core business for aged care** – achieving financially sustainable and quality care
- **Enabling choice and control** - strategies to prepare your organisation in tackling the balance of risk and duty of care
- **Build dementia care capacity** – how to manage change effectively and shift models of care

FEATURED SPEAKERS

 Dr Stephen Judd Chief Executive Officer HammondCare	 Linda Justin Director of Practice & Quality Uniting	 Glenn Rees Chairman Alzheimer's Disease International	 Professor Henry Brodaty Ageing & Mental Health Dementia Collaborative Research Centre UNSW
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WORKSHOPS

 Adapting models of care for better dementia outcomes 5.30pm More information >	5th Oct
 Implementing national strategies to improve dementia care 9.00am More information >	7th Oct

Book by 15th July & SAVE \$400
Bookings from the website:
www.criterionconferences.com/event/sds



Conference Diary

National Pain Week

25-31 July

"You look good. How do you feel?"

Palliative Care Victoria State Conference

July 28th & 29th, Melbourne

"Inside, Outside – keeping the essence of Palliative Care alive"

Aged Care Services Australia National Summit

Grand Chancellor Hotel, Hobart

September 6th – 9th

Early bird registrations now open at

www.acsanationalsummit.com.au

Palliative Care Nurses Australia Conference

September 11th – 12th

Canberra

MND National Conference 2016

"Care, Collaboration, Communication"

September 12th

Melbourne

Details from info@mndaust.com.au

Palliative Care NSW Biennial State Conference

"Transforming the Landscape"

October 12th – 15th

Broken Hill, NSW

COTA Strengthening Dementia Services

October 5th – 6th

Rendezvous Grand Hotel, Melbourne

Info from COTA at

www.criterionconferences.com/events/sds

3rd Oncology Massage Conference

Thursday 27th – Saturday 29th October

The Mercure, Braddon, Canberra

MND Association Education Conference

October 24th

Kettering Park Hotel, Northamptonshire, UK

www.mndassociation.org/edconf10

The National Palliative Care Conference 2017

Will be held in Adelaide



The media were out in force at the Hobart Expo when it became the venue for an election promise

Palliative Matters launched

Palliative Care Australia has launched a new online publication with stories about living, dying and palliative care. It promises to inspire and inform, whether your interest in palliative care is personal or professional.

See palliativecare.org.au/palliative-matters.



Developing organisational guidelines for the prevention and management of suicide in clients and carers receiving palliative care in Australia

Emeritus Professor Margaret O'Connor AM, Emeritus Professor of Nursing, School of Nursing & Midwifery Monash University, has recently published a new article: O'Connor M, Groom J, Watson M, Harris P. (2016) *'Developing organisational guidelines for the prevention and management of suicide in clients and carers receiving palliative care in Australia'*. American Journal of Hospice & Palliative Care. 33(3) 252-255