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Palliative Care ACT

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Thank You! Thank you!



Since our last edition Palliative Care ACT would like to thank all the generous individual donations received. Acknowledgment is also given to the support of the following businesses and organisations

- ◆ John James Memorial Foundation
- ◆ Lennox Motors Phillip
- ◆ Federal Monday Group
- ◆ William Cole Funerals
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- ◆ Southern Cross Club
- ◆ Excelerated Consulting
- ◆ National Press Club of Australia
- ◆ ACT Medicare Local

Your generosity and support is appreciated.

Mission

Working with individuals and organisations to facilitate, promote and improve palliative care in the ACT and to offer compassion and support to the terminally ill, their families and carers

Palliative Care ACT Inc.



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From
the
President
John Hanks



advocate and educate; advocating for change and educating the public and the Government of the benefits which arise from accepting a palliative care approach for those with a life-limiting illness.

Further significant advancement in palliative care occurred on Tuesday 14 February 1995 (Valentine's Day) when the then Chief Minister for the ACT, Rosemary Follett, opened the first ACT Hospice on the site of the old Canberra Hospital. In her speech the Minister thanked the Association for its commitment to the establishment of the Hospice. She stated that Shirley Sutton and Heather Wain (who died only recently) had been amongst the leaders in the Association's efforts.

The Year Ahead

2015 is shaping up to be a busy year and an important one for Palliative Care ACT.

There is the opportunity to look back over the 30 years that the Association (or a fore runner to the organisation) has been in existence, to reflect on our many achievements over those years and to pay tribute to all those who have contributed to delivering the quality palliative care services that Canberrans receive today.

While reflecting on past achievements we cannot lose sight of the fact that much remains to be done to educate the public about end-of-life choices and to improve and extend palliative care services for those diagnosed with a life-limiting illness who live in their own home or reside in an aged-care facility.

A major advance in palliative care in the ACT occurred on 1 April 1985 with the commencement of the Home-Based Palliative Care Program. Before the Association officially came into existence its volunteers played an important role in this program. When the Association formerly commenced on 25 September 1985 its primary functions, in addition to the provision of a volunteer service, were to

At that time Janet Turner was appointed Co-ordinator of Volunteers and the overseer of training of volunteers for the hospice as well as those for the Home-Based Program. One of the volunteers in the Home-Based Program, Stephanie Hayes, offered full time live-in support to dying persons and their families.

It is only right and proper that the hard work and achievements of the early pioneers are recognised and celebrated at functions throughout the year. I encourage you to join in the celebrations that will take place over the next 18 months.

In addition to celebrating past achievements it is most important that we also acknowledge the work currently being undertaken by volunteers and staff in delivering high quality palliative care services to the people of Canberra.

The Association has much to be proud of.

John Hanks

Message from the General Manager

As John has indicated, 2105 is a big year for Palliative Care ACT as we celebrate our 30th year of formal incorporation as an association.

I noticed with some wry humour that the TV serial *Neighbours* is also celebrating its 30th anniversary this year, but it could be said that being a good neighbour and caring and supporting people at the end of their life have much in common. Apart from mullets, shoulder pads, extreme weather events and some questionable music, 1985 also saw the:

- first Live Aid concerts;
- Brixton Riots;
- introduction of Capital Gains Tax in Australia;
- approval of the first blood test for AIDS;
- discovery of the wreck of the Titanic;
- maiden flight of the space shuttle Atlantis;
- sinking of the Rainbow Warrior; and
- rise of Mikhail Gorbachov to lead the Soviet Union.

As I write we are busy finalising plans for the Annual Volunteer Dinner which will take place at the Southern Cross Club on 21 May.

This edition of Mosaic brings a book review kindly contributed by our President. We welcome other reviews on topics relating to palliative care, loss,

ageing, grieving, volunteering or on other matters you may think relevant. I am busy compiling a list of useful titles, articles and links which I hope soon to be able to bring to you in a readily useable format.

Our Secretary, Jenni McMullan, has contributed an article summarising the Planning Day held by the Board. As you can see it has resulted in some challenges ahead as we work to strengthen our existing services, plan for growth and step up our community education, marketing, communications and fund raising.

You may have noticed that I have announced the membership of the Volunteer Committee. Again, I appreciate both your patience and your interest and invite you to submit items for discussion either direct to me or to a member.

Best wishes

Penny Farnsworth
General Manager

PCA e-News

To read the latest edition go to:

www.palliativecare.org.au, News, Newsletter

PCA e-News 30 April 2015

Or:

[PCA e-News 30 April 2015](#)

13th Australian Palliative Care Conference

Melbourne 1-4 September 2015

PCA says five top reasons for coming to the 13th APCC:

1. World leaders in palliative care. Speakers include Joachim Cohen, Gail Eva and David Currow.
2. The latest research and innovation from the sector.
3. Unrivalled networking opportunities.
4. Four days of learning and professional development.
5. Challenging and inspiring debate on the big topics facing palliative care.

There will be a pre conference day on Tuesday 1 September with half day workshops covering a wide range of topics. An additional registration cost applies for these sessions.

I will write shortly to volunteers about PACT's participation.

Book Review

Being Mortal by Atul Gawande

Being Mortal, by Atul Gawande, a surgeon in Boston and a professor at Harvard Medical School, is a fascinating and very informative book about death, dying and end of life choices. It challenges us to think about what it is like to get old and die and how modern medicine has changed our thinking about mortality for the worse.

Dennis Pacl, until recently a Palliative Specialist at CHH, recommended this 2014 publication to me when he visited Canberra in January and Penny Farnsworth, General Manager at PC ACT loaned me her copy.

Gawande states that modern scientific capability has profoundly altered the course of human life, with people living much longer than at any time in history. Scientific advances have often, however, turned the process of aging and dying into a medical experience managed by health professionals who can be poorly prepared for the task.

As recently as 1945 most people died in their own bed at home surrounded by family and visited by both doctor and clergy. That has changed significantly. Those who die at home today are likely to have died too suddenly to make it to hospital or they were too isolated to get to where help could be provided.

"In the past few decades," Gawande writes, "medical science has rendered obsolete centuries of experience, tradition and language about our mortality and created a new difficulty for mankind: how to die."

He goes on to say that one does not have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. "The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. They are spent in institutions – nursing homes and intensive care units – where regimented, anonymous routines cut us off from all the things that matter to us in life."

He adds that we often allow our fates to be controlled by medicine, technology and strangers.

While Gawande writes about his experiences in the United States, his comments have much relevance to Australia. On a positive note we in Canberra have to some extent at least recognised the problem articulated so well by Gawande by facilitating palliative care e.g. our hospice and home based palliative care arrangements.

There is, however, much more that needs to be done in educating the public about end of life choices and in improving and extending our palliative care services particularly in the home and in aged care facilities.

Palliative Care volunteers play a significant role here.

See also an informative video featuring Dr Gawande, produced by the American PBS at <http://www.pbs.org/wgbh/pages/frontline/being-mortal>

John Hanks

Vale Anna, Heather and Elaine

Sadly 2014 saw the passing of Heather Wain, former President of Palliative Care ACT, and Anna Wellings Booth OAM. Both women made an enormous contribution towards improving the lives and futures of women suffering breast cancer.

Another valued volunteer Elaine Pringle also sadly died this year. She is remembered for her gentleness to the end.

They will be missed but their legacies live on.

DEATH CAME GENTLY

Martin Flanagan*

My mother died around one o'clock in the morning. I was asleep on a mattress at the foot of her bed, the others having left about 90 minutes before. Dad, by choice, died alone. Mum's deathbed was a crowd scene, kids and grand-kids in the half-lit room, one person on either side of Mum, holding her hands.

Mostly, we sat in silence but that last evening we talked aloud. Voices were Mum's music. She loved what the Irish call the craic, the excited talk, the laughter, the fun of being together. Her last coherent words, with all of us in the room, were, "Thanks everyone. I've had a lovely time."

I'd only been back from London 36 hours when my sister Mary rang and said, "You'd better come." The last gathering had begun. It lasted three days. On the afternoon of the second day Mum spoke to each of us in turn. Her thinking had been confused in some ways over the past year but now she was as clear as light. She wished us good luck. We were travelling on but she wouldn't be coming. She said something pertinent to each individual. She wasn't scared but she said, "I'm going to miss you all."

Around 11.30pm on the third day, one of my nieces, Jean, said that maybe she would leave Mum and let her rest. I had volunteered to sleep that night in her room. With the others gone and the room dark, I lay for a while, listening to her every breath. It was like watching an old hand write its last words, the pen scratching on the paper.

I was still jet-lagged and I could feel the black ink of

tiredness behind my eyes but, even so, I managed to wake every half hour or so. I was conscious of her breathing slowing, then I thought I heard it no more and forced myself to wake. It was 1.04am. I could detect no breathing and rang for the attendants. They were initially uncertain so the younger of the two took out a stethoscope and, having listened to Mum's chest, said to me, "Your Mother has passed away" She said it with great delicacy and care but it was still the moment the earthquake of emotion hit.

Three days later, as I write this, I count myself lucky – lucky we had her for as long as we did, lucky to have been with her at the end. Mum was 95; at such an age, death is not tragic – it's natural.

When we were young, Mum had fire and energy, but that's what it took to keep the show on the road. She had four kids under the age of eight and then two more arrived unplanned. As her kids got older Mum mellowed. In the end, after multiple strokes and seizures, all that was left was love.

If I have one conclusion in the wake of this experience, it's that we fear death too much in this culture. We hide it away, avoid it. In recent times, men have started to realize witnessing birth can be one of life's defining experiences. So can witnessing death.

*Martin Flanagan is a senior writer at The Age.

This article appeared in The Canberra Times, Forum, page 4, Saturday 22 November, 2014.

(Submitted by Jenifer Hanks, Palliative Care Volunteer, CHH)

The Board's Planning Day 2015

As part of its governance processes, the Board meets annually to review its priorities for the year ahead.

In line with this, the annual Planning Day took place on 7 February at the Tom Elvin Centre. The whole Board was present together with Penny Farnsworth, our General Manager.

The methodology used to determine the priorities was discussed at an Executive Meeting in January and it resulted in three discussion themes being identified as follows:

- Stakeholder Engagement
- Financial Independence/Resilience
- Operational Requirements

The Board, together with the Penny, broke into small working groups to unpack each of these themes, using a discussion matrix which included:

- Priorities
- Rationale
- Challenges/Risks
- Strategies to Resolve Challenges
- Measures of Success
- Responsibility

The group as a whole then discussed the different understanding and priorities of each small group and agreed a maximum of three key findings that would be the focus of the Palliative Care ACT team for the next 12 months. The priorities against each theme are as follows:

Stakeholder Engagement

- Develop a stakeholder/marketing plan
- Plan celebrations for the 30th anniversary of PC ACT
- Develop staff and volunteer workforce and associated governance plan

a greater awareness of PC ACT and therefore political (and funding) support. We are seeking here for the community at large to become an enthusiastic advocate for PC ACT. We plan to raise our profile through the 30th anniversary celebrations and involve our stakeholders. The third dot point relates to the development needs of our staff and volunteers as well as looking at how we might attract other volunteers as demand grows and/or as existing volunteers retire.

Financial Independence/Resilience

- Communication plan for engaging with sponsors
- Sponsors plan for long term funding streams
- Definition of financial sustainability

We all know that Government budgets are tight and with the current deficit we need to diversify and examine our options for other sources of funding. These priorities are about engaging with our sponsors to achieve long term financial resilience.

Operational Requirements

- Develop Business Plan for 2015-2016
- Undertake Service Review

In line with good governance, we will develop our business plan before June, setting the scene for the medium term. We also plan to have an external review of our services and how we deliver them. This will enable us to assess whether we are meeting the quality targets we set ourselves. A report card on our performance will also assist us in our bids to government and other organisations for both financial and in kind support.

If anyone has any questions about the Planning Day or the priorities we have established, please phone Penny Farnsworth on 6255 5771.

Essentially here we are seeking to build and maintain

PC ACT welcomes Julie Elliott, Assistant General Manager



Palliative Care ACT is pleased to welcome Julie Elliott, who will shortly be taking up the role of Assistant General Manager.

Julie has 19 years' experience working in the Not-for-Profit sector and possesses qualifications in management, community services, service coordination,

business administration, training and workplace assessment. She began working in the not-for-profit sector as a community carer looking after elderly people in their homes. Julie remained with this organisation for 15 years in several roles before commencing as the manager of its Canberra branch. Three years ago she

started a new job as the Manager of Home and Community Services with Mercy Health, taking on the challenge of building up the presence of the organisation in the ACT.

Julie looks forward to continuing and building on this experience in her new role with Palliative Care ACT.

Julie's interests include reading, listening to music, travelling and spending time with family. She volunteers with local charitable programs such as the *Angel Gown Australia Program* and the *Tutu Australia Program*. The *Angel Gown Program* transforms donated wedding dresses into tiny gowns for babies who have passed away, and the *Tutu Australia Program* converts the tulle left over from wedding dresses used in the *Angel Gown Program* into tutus for special needs children or children who are suffering a long term or terminal illness.

Reprinted from Palliative Care Australia's eHospice

Jodi Rose explains why she's dying to talk

I am dying to talk about dying because I believe having this important conversation takes us to the brink of what it means to be human. It is not an easy task to contemplate the transition from life to death, as it challenges us to face our own mortality and that of our loved ones. However, many of us will be thrust into the caring journey and if we are able to talk about it now, before the fact, there is much to gain.

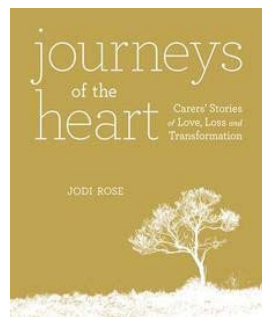
Are we too busy living life so fully that we don't often entertain having this discussion? In many ways talking about dying has been hushed in our society. Though medical advancement focuses on fighting disease, what about having the discourse about the art of dying? Now as never before I sense a growing readiness and need for people to engage in issues regarding end of life transitions. It's no surprise because as part of the big picture, we all are touched by loss through our lifetime.

The world I once knew changed dramatically more than three years ago after the passing of my husband. I never expected what happened, as I was married to Murray Rose, a man who was seemingly invincible. I suppose his being an Australian swimming legend in the 1956 and 1960 Olympic Games created an expectation in my mind that did not include his

passing away at age 73 from acute myeloid leukaemia. The amount of time from diagnosis to his last breath was tragically 2½ months. Our GP, haematologist and St Vincent's Sacred Heart Health Service palliative team became a collective force in my managing what was to come. Because of their model of care I was able to serve Murray at home.

Having lived in Australia for over 20 years now I am grateful beyond measure for the services which allowed me to take on the most important task I would ever be asked to accomplish. Whether caring for a loved one at home, a hospice or hospital, having the services, the tools and the insight of others can make an overwhelming difference.

Jody Rose's book *Journeys of the Heart: Carers' Stories of Love, Loss and Transformation* is available online and at most bookshops.



Donation from staff of National Press Club

On Thursday 2 April John Hanks, Sue Bromhead, Katrina Smithers and Penny Farnsworth had the very great pleasure of participating in a cheque presentation ceremony at Clare Holland House. On a beautiful morning we received a donation of \$5000 from the staff and Board of Directors of the National Press Club.

The funds will be used to support our programs, including the valuable massage service provided to clients at Clare Holland House, in their homes or in Residential Aged Care Facilities.

The Board and staff of Palliative Care ACT gratefully express their appreciation for the kind donation, and look forward to continuing a positive relationship with the National Press Club.



From left to Right: John Hanks, Hannah Porter NPC Marketing Coordinator, Sue Bromhead, Paul Butler NPC Food & Beverage Manager, Anna Johnston NPC Events Manager, Penny Farnsworth, and Katrina Smithers.

Upcoming Events

The Annual Volunteer Dinner will be held on 21 May 2015. Southern Cross Club Woden 6.30pm for 7pm. Please RSVP to Andrea by phone 6255 5771 or email andrea@pallcareact.org.au.

National Volunteers Week is 11-17 May 2015.

The ACT Volunteer of the Year Awards are 14 May 2015.

National Palliative Care week is 24-30 May 2015. The theme is "Dying to Talk – Talking about death won't kill you". (See page 4 for further details).

The 13th Australian Palliative Care Conference is 1-4 September 2015. The theme is *Fit for the Future*.

30th Anniversary for Palliative Care ACT is 1 October 2015.

30th anniversary for PACT

As noted earlier, 28 September this year marks the 30th anniversary of the incorporation of the ACT Hospice Society, the original organisation which over time has become Palliative Care ACT. There have been many achievements over the last 30 years that we should remember and celebrate. A small 30th Anniversary Committee has been formed under Board member and volunteer Matt Tripovich, which is developing a program of activities to commemorate the

achievements and the people whose vision over the years has got PACT to where it is today.

A core event will be a 30th Anniversary dinner at the Canberra Southern Cross Club Woden on Thursday 1 October 2015. Please mark that date in your diaries now and look out for more information about the dinner and other events during the rest of the year.

If you have any ideas or memorabilia to contribute please contact Matt or Penny.

Death Café at Kippax Uniting Church (KUC) – 15th February 2015

Thanks to Hannah Duggan, the wonderful Joan Scott and Ruth Williams who spoke at several Kippax Uniting Church services, managed bookings and many other liaisons a wonderful 38 people attended this death café. A total of seven volunteers and two staff helped make the evening run smoothly. Catering industries supplied the food for the evening and did so in abundance.

Medicare Local also sponsored the food budget.

There was much laughter and some serious discussions. Feedback was largely positive as evidenced in the evaluation sheets.

Given that a large percentage of attendees were from KUC it was very much a community event.

Many thanks to all who helped make it a successful event.



An activity within a small group

National Palliative Care Week 24 to 30 May

Theme

To commemorate National Palliative Care Week this year, Palliative Care Australia (PCA) has adopted the theme Dying to Talk – talking about death won't kill you.

PCA's website says:

During National Palliative Care Week, Palliative Care Australia (PCA) is encouraging Australians to break the last taboo and talk about dying – it won't kill you.

PCA wants to normalise death and dying. To do this Australians need to feel more comfortable talking about what their wishes and needs are as they approach end of life. Australians need to be comfortable and confident to ask for the care they want.

PCA encourages all Australians to use National Palliative Care Week as a conversation starter – get together with those close to them, celebrate life (have a meal or a coffee) and talk about death.

- *How do you want to be cared for?*
- *What values are important to you?*
- *What do you want when you die?*
- *Have you considered if you wish to be buried or cremated?*
- *Do you want to pass away at home or in a hospice?*
- *Have you established a power of attorney?*
-

All these questions and more need to be addressed to ensure Australians can aim for best death possible, with their family and friends aware of their wishes.

So, during National Palliative Care Week; take a moment to think about death. How you want to die and how you want to be cared for to live well.

Keep an eye on the PCA website <http://www.palliativecare.org.au/Ourwork/NationalPalliativeCareWeek.aspx> for updates on events during the week.

Twilight talk

Clare Holland House and PC ACT have joined forces to present a stimulating discussion on Propagating Palliative Care in a developing country. Dr Suharsha Kanathiagoda, who recently commenced work at Clare Holland House and Calvary Hospital, will share his experiences and insights on establishing palliative care services in Sri Lanka.

Suharsha is the founder and Chairman of the Shanthi Foundation, which aims to provide culturally appropriate palliative care throughout the world. Amongst other things, the Foundation provides palliative training to doctors, nurses and allied health staff through the Australian Institute of Palliative Medicine and other partner organisations in developing countries including India and Sri Lanka; establishes community palliative care units to help care for people in their own homes; and works on a number of programs dealing with oral cancer and chronic kidney disease. In Australia the Foundation conducts palliative care clinics/visits in remote regions and in **Aboriginal** communities.

PCACT is keen to broaden its services into the many culturally diverse areas of our community, and Suharsha's talk and the interactive discussion that will follow it are sure to bring some good ideas on how we might proceed.

The free event will be held at the National Portrait Gallery, King Edward Terrace, Parkes, ACT 2600 on Thursday, May 28, 2015 from 6:00 PM to 8:00 PM (AEST). Light refreshments will be provided.

To register for what promises to be a stimulating and informative event please register at the link set out below:

<https://www.eventbrite.com/e/propagating-palliative-care-in-a-developing-country-sri-lanka-tickets-16669417677>

The history on how this newsletter became the Mosaic

This newsletter has been named Mosaic since its second edition in March 1987.

MOSAIC

Listening in Perth and Sydney to Dr. Derek Doyle, explaining staff support at St. Columbias, Edinburgh as being a situation as he put it, where "We love each other". How often did I make the same comment about the team at Mount Carmel. I see this type of support in all the evolved hospices now emerging throughout Australia and I liken the hospice team to a MOSAIC.

A MOSAIC is made up of insignificant pieces of marble or stone, not strikingly beautiful in themselves, but so arranged that a beautiful pattern emerges. Each piece needs the surrounding pieces to show it up to its full beauty.

The part and the whole are interdependent so it is not by self assertion but by co-operation, by working humbly, unselfishly and harmoniously with others that we can best add to the beauty of our life and work together. We may be needed for the background of the MOSAIC only, perhaps as volunteers, and if we refuse to take our place the pattern would be not only imperfect, it would be incomplete. The design would lose in power and strength.

The then Palliative Care Society called for suggestions in the first and then unnamed edition, offering a prize of a dinner for two. Patricia Cooper of Monash won the competition and credited the following as her inspiration. The words remain as relevant and moving today as they were some 27 years ago.

2015 membership renewal due 1 July

An active and engaged membership helps Palliative Care ACT speak with a strong and authoritative voice when engaging with the ACT Government, other agencies and organisations in providing quality palliative services and support to our community.

As a financial member, you will be kept abreast of exciting developments in the area of palliative care through the quarterly Mosaic newsletter, and you will be entitled to have a say at the General Meetings of the Association.

Your ongoing membership and support is important in supporting PACT's work. Our two community Day Hospices at Curtin and Jamison continue to provide a safe and supportive environment for palliative care clients to enjoy a range of activities, therapies and relaxation, and vital respite opportunities for caring family members, and the number of clients attending

each week is growing steadily. We are increasing our support to clients in their home and in residential aged care facilities. An initial trial palliative care volunteer program at the Canberra Hospital has been successful, and plans are underway to expand the service in the next year. A number of very successful Death Cafes have been held at which members of the Canberra community can become more comfortable talking about the issues of death and dying, and more will be held in the future.

A membership application/renewal form is enclosed with this edition of the Mosaic. Please take the time to read the information in it, fill in your details and select the most convenient form of payment. Please then return the form (and your cheque if that is your preferred method of payment) to Palliative Care at the address on the application form as soon as possible.

By being a financial member of Palliative Care ACT, your financial contribution will help us to help others.

The John James Memorial Foundation and Lennox Motors Phillip help PC ACT get more mobile

On 28 January this year our President and General Manager were delighted to participate in the official handing over of our new vehicle, a Skoda Yeti. The car was very generously donated by the John James Memorial Foundation, represented by Phil Greenwood at the ceremony.

Lennox Motors Phillip also contributed significantly to the donation. Lennox was represented at the ceremony by Colin Yapp, Peter Munday, Bob

Penrose, Shaun Cox, Connor Gibbs-Patterson, Peter Axiom and Ann Tompsett.

Despite its somewhat scary name, the Yeti is a very reliable and practical vehicle which more than meets the needs of PC ACT staff and clients, from general business to assisting with transporting clients, including those with limited mobility.

The Board and staff of PC ACT gratefully acknowledges the generosity and support of the John James Memorial Foundation and Lennox Motors Phillip. We look forward to continuing our positive partnerships into the future.



John Hanks President Palliative Care ACT, Penny Farnsworth General Manager Palliative Care ACT, Peter Axiom, Lennox Motors Company Director, Phil Greenwood CEO John James Memorial Foundation.