



May 2008

Volume 1 Issue 1

**National Palliative Care Week 2008, 25-31 May**

The Society in collaboration with Clare Holland House will be holding a twilight seminar to mark National Palliative Care Week 2008. Dianne McKissock, OAM, Co-Director of the Bereavement C.A.R.E. Centre and Co-Clinical Director of The National Centre for Childhood Grief—known as 'A Friend's Place', will be the guest speaker.

Dianne will be speaking about 'The Grief of Our Children' at the Burns Club, Kett Street, Kambah, on Tuesday, 27 May, between 6 and 8pm .

RSVP is essential by 21 May on 62647355 for catering purposes.

This seminar is supported by the Australian Government Department of Health and Ageing.

**INSIDE THIS ISSUE :**

<b>PCA Update</b>	<b>2</b>
<b>• Euthanasia Laws (Repeal) Bill</b>	<b>2</b>
<b>Advance Care Plan ACT</b>	<b>3</b>
<b>Superannuation early release</b>	<b>3</b>
<b>Foreshore Garden Project, CHH</b>	<b>4</b>
<b>Society's Volunteer Program</b>	<b>4</b>
<b>Society's Council</b>	<b>4</b>
<b>Events for your diary</b>	<b>4</b>

**WELCOME FROM THE PRESIDENT**

A BIG warm welcome to our new look Mosaic! This newsletter aims to keep you informed and up to date with palliative care issues and events.

Several years ago, the Society published a newsletter with the same title and it is only right and fitting that we carry on with the tradition and use the name 'Mosaic'.

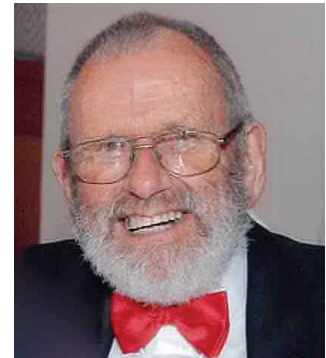
The word mosaic brings to mind a decorative art involving small pieces of glass, stone, jewels or other material. Putting together what seem to be unrelated, mismatched and at times broken pieces, building itself into a beautiful mosaic. In the same breath, I like to think that we, as a Society – people from different walks of life, cultures and background with diverse experiences and knowledge – joining

together we make a difference to the world we live in.

The Society has been very active for the first part of the year. To participate in the ACT Senior's Week 2008, the Society held an information morning tea session on 9 April at the Hellenic Club, Phillip.

The title of the talk was 'Understanding and demystifying palliative care'.

The Society also held a display stand at Kingston Depot on 10 April - part of ACT Senior's Week events organized by COTA. This was a good opportunity to meet the general public to promote awareness and a better understanding of palliative care and the services available here in the ACT.



Bill Packard, President

**Update on ACT Palliative Care Strategy 2007-11**

The Society is pleased to be part of the ACT Palliative Care Strategy 2007-2011 Implementation Steering Committee. The Steering Committee was established to provide input and guidance to ACT Health's Portfolio Executive on the process of implementing the ACT Palliative Care Strategy.

**EXPANSION OF PALLIATIVE CARE INTO RESIDENTIAL AGED CARE FACILITIES**

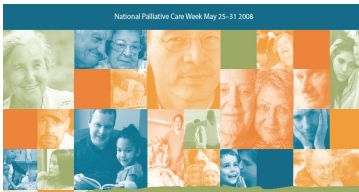
The Society is pleased to read in the recently released ACT Budget that a sum of \$579,000 has been put aside over four years for the expansion of palliative care services. The funding will provide for the addition of a Palliative Care/Aged Care Clinical Nurse Consultant and the addition of a Palliative

Care/Aged Care Volunteer Coordinator. These two positions were among recommendations from the Society to the ACT Government in a 2008-2009 Pre Budget Submission. It is no secret that there is an obvious gap in residential aged

care facilities where a great need exists for more palliative care services, especially palliative care volunteers to support residents who are dying. The Society welcomes the funding provision from the ACT Government to provide better support for our aged care residents.

## Excerpts from Palliative Care Australia E Bulletins


National Palliative Care Week, May 25-31, 2008



Palliative Care  
**A Matter of  
Life and Death**

What is palliative care?  
What can I say? What can I do?  
Asking questions can help.

For more information about living with, caring for or working with someone with a terminal illness contact 1800 660 055 or go to [www.palliativecare.org.au](http://www.palliativecare.org.au)



Supported by the Australian Government Department of Health and Ageing

## Submission into the Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill

The Senate Standing Committee on Legal and Constitutional Affairs is undertaking an inquiry to provide organisations and individuals the opportunity to comment on the Euthanasia Laws (Repeal) Bill 2008, which seeks to repeal a previous Act preventing the Northern Territory and Australian Capital Territory Legislative Assemblies from legalising voluntary euthanasia.

Palliative Care Australia's submission noted that the ethical issue of whether a person should have the right to choose the time, place and means of their own death is a separate issue to the provision of quality care at the end of life.

However, Palliative Care Australia believes that much of the community interest in voluntary euthanasia is sparked by a need for assurance that

pain and suffering will be relieved and that individual end of life decisions will be respected – assurances that can in many cases be provided through the access to quality palliative care. Informed community discussion about euthanasia cannot be had until quality palliative care is available for all who require it and there is enhanced community understanding of existing end of life decision making options, including advance care planning. Palliative Care Australia recommended that the Committee:

- commit to promoting open and frank community discussion about death and dying through ongoing communication initiatives to increase community capacity to consider and plan for end of life;

- conduct an inquiry into the barriers to greater use and respect of advance care plans and directives and mechanisms for overcoming them; and
- advocate for reform and resources to enhance access to needs-based palliative care.

To read Palliative Care Australia's submission visit

[www.palliativecare.org.au](http://www.palliativecare.org.au)

- Excerpt from  
Palliative Care  
Australia  
E Bulletins April 08



## 2008 NEW PHARMACEUTICAL BENEFITS LISTING - ACTIQ

Actiq (fentanyl citrate) is an alternative for treating breakthrough cancer pain when additional doses of morphine produces intolerable side effects in cancer patients.

Because Actiq is administered as a lollipop and dissolved through the cheek, it takes effect within 5-10 minutes.

In a media release from Actiq's manufacturer, Palliative Care Specialist Dr Sarah Pickstock said "Actiq 9u" may have significant benefits for any patients with cancer related pain because of its rapid onset and short duration. It may help give patients a greater degree of control and flexibility with their dosing,

thus improving their quality of life."

This unique treatment which has been used in Australia since 2002 is now available through the Pharmaceutical Benefits Scheme to benefit all Australians receiving palliative care.



**Palliative  
Care  
Australia**

## ADVANCE CARE PLAN: (Australian Capital Territory)

The Respecting Patient Choices Program is promoting advance care planning in the Australian Capital Territory. This program is about the promotion of autonomy and dignity and not about euthanasia or suicide. You have the right to make decisions about your health care, now and for the future. Medical treatment should only be given with your fully informed consent and you have the right to refuse treatment. If, in the future, you become unable to express your choices for treatment, your doctors and family/friends may not know what you would want. An Advance Care Plan gives you the opportunity to record, ahead of time, your choices. An Advance Care Plan ONLY comes into effect if you lose legal capacity to make decisions about your medical treatment.



[www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

The three ways to record your choices in an Advance Care Plan are:

1. Appointing an Enduring Power of Attorney (EPA)
2. Documenting your wishes in the Statement of Choices
3. Completing a Health Directive under the Medical Treatment (Health Directions) Act 2006.

Before completing the Advance Care Plan, take time to read the information carefully. It is important that you discuss your values and beliefs and the content of the Advance Care Plan with the person/s whom you wish to appoint as your attorney/s under an Enduring Power of Attorney. It is important that you involve your attorney /s , and you discuss your Advance Care Plan together so that they understand and respect your choices.

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ACT Health  
The Canberra Hospital  
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### How to make an Advance Care Plan : ACT

In the ACT, the individual can write legally binding directions about their medical care on the "Directions, Limitations and Conditions" section of the **enduring power of attorney form** when they are completing an enduring power of attorney. If they wish only to refuse treatments and not to give consent to some treatments, they can:

- Complete a Health Direction in the documents under the Medical Treatment Act 2006 and not appoint the Powers of Attorney Act or
- Complete the "Refusal or withdrawal of Medical Treatment" section of the **Enduring Power of Attorney** document under the Powers of Attorney Act 2006.

The documents under the Medical Treatment Act and the Powers of Attorney Act are legally binding. For more information, visit Public Advocate ACT website:

[www.publicadvocate@act.gov.au](mailto:www.publicadvocate@act.gov.au) or phone 62070707



You can view a  
Respecting Patient Choices  
DVD on their website.  
[www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

## EARLY RELEASE OF SUPERANNUATION BENEFITS FOR PALLIATIVE CARE PATIENTS UNDER THE AGE OF 55

Members of superannuation funds, and depositors in Retirement Savings Accounts, who are terminally ill, can apply to have their preserved superannuation benefits released tax free subject

to meeting certain conditions. Application for release of benefits in these circumstances should be made directly to the individual's superannuation fund or retirement savings account provider.

For more information, consult your accountant or your superannuation fund manager or call the Australian Prudential Regulation Authority on:-

1300 131 060

### CareSearch

CareSearch is an Australian Government funded project to improve the evidence available to palliative care clinical practitioners, researchers and educators nationally. It is also a very useful internet resource to provide patients, carers, families and friends information on disease, financial, national resources, wills and funerals advice etc.

[www.caresearch.com.au](http://www.caresearch.com.au)

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## Society's Volunteer Program

The Society is pleased to acknowledge the ongoing robust nature of its volunteer program. Robust in that there is always a waiting list of people keen to train and participate, and robust in maintaining a high retention within the community of experienced volunteers. With 14 new volunteers currently being orientated, the number in the program is 115. They continue to contribute at Clare Holland House (CHH), on the home based program, with transport and many other services. Volunteers donated over 2,500 hours at CHH in the first three months of 2008, and 600 hours to support people at home. Recently the co-ordinators have been working with ACT Health's Community Partners Program to train volunteers from Villaggio Sant' Antonio, St Nicholas Residential Aged Care and members of Asian communities in aspects of palliative care support. This has been very rewarding and has prepared the way for the work of the new Co-ordinator of Volunteers of Palliative Care/Aged Care in the ACT.

### Mission

*Working with other organisations and services to facilitate, promote and improve excellent palliative care in the ACT and to offer compassion and support to the terminally ill, their families and friends.*

A group of 22 volunteers recently attended the NSW Palliative Care Volunteers Conference in Sydney. The day was as much about hearing presentations on the topic "Dignity", as it was about networking and enjoying the company and conversations with other volunteers. The Society was able to pay the modest registration fee for our participants.

Eighty seven professional massages have been provided to patients/carers between January and April. The Society sub contracts with qualified massage therapists to provide this service in CHH or the patient's home. Monies from our valued community fundraising partners are allocated for this purpose and we specifically acknowledge the Federal Golf Club Members Charity Committee and the Canberra Southern Cross Club. Many volunteers also offer basic hand and foot massage to patients as part of their companionship role. A robust group indeed!

### We are on the web!

[www.pallcareact.org.au](http://www.pallcareact.org.au)

### ACT Palliative Care Society Inc.

Shirley Sutton, AM, PSM Patron

#### Council Members

Bill Packard, OAM	President
Brian Hill, AM	Vice President
Dr Ian Sykes	Treasurer
Linda Denman	Honorary Secretary

Jenny Hall  
 Sister Teresa Hussey  
 Marg Sharp  
 Vivienne Sinderberry  
 Dr Andrew Skeels  
 Bradley Smith  
 Sue Wood

### CLARE HOLLAND HOUSE -

A landscaped garden on the shore of Lake Burley Griffin to the south of Clare Holland House due for completion in a few months will provide a pleasant environment for reflection, contemplation and gatherings for patients, their families and friends. This project was first identified and began as a private initiative by the family of a patient, Sally Riding. With strong support from the Rotary Club of Canberra—Weston Creek (manager of the project), Clare Holland House (part of Calvary Health Care ACT) partnering with the National Capital Authority, Department of Territory and Municipal Services, the garden was implemented as a community based project with the ACT Government responsible for the ongoing maintenance. The cost to complete the garden is estimated at approximately \$250,000.

### Events for Your Calendar

- **Annual General Meeting – Tuesday, 6 November 2008 'Orion Room', Canberra Southern Cross Club at 6pm.**

**Guest speaker - Geoffrey Pryor, Cartoonist, formerly of The Canberra Times.**

### Don't miss it!

- **Ageing and Spirituality: A Diversity of Faiths and Cultures Conference by Centre for Ageing & Pastoral Studies 17-20 August 2008 Rydges Eagle Hawk Resort, Federal Highway, Sutton For more information, Phone 6273 8551**

A young Welsh mother left a hand written mummy manual to help her husband bring up their 7 year old daughter. This touching three page manual published in a Welsh local newspaper covered some of the finer points of motherhood that her husband might not have thought of:-

'Be sure her hair is tied back for school, neat parting, no bump, smooth with tail comb if necessary. Check for nits regularly, bath and hair every other night at least, no child of mine to be smelly. Make sure you serve food with vegetables/peas, get fruit down her, don't let her live out of cans, noodles and toast....'

The list goes on but it ends with her telling him to keep in touch with her parents, friends and their daughter's god parents or 'I'll haunt you'.

*Transcript from Health Report  
 ABC Radio National  
 5 May 2008  
 The Heart Will*

*Here's to lights and virtues  
 Here's to truths yet to be known  
 Knowledge to light the darkness  
 The search for things of your own  
 Here's to lights and virtues  
 Here's to reaching higher ground  
 A life of hope and purpose  
 Here's to strength yet to be found  
 Honour -- though it goes unrecognized  
 And truth -- though liars abound  
 The pleasure of love and friendship  
 The courage to be alone*

*- From the lyrics of Lights and virtues  
 by Jackson Browne*