

newsletter

May – June 09



**Palliative
Care
Queensland**



President's Report



Hello Everyone. I have to admit writing this article while watching birds enjoy my garden on this lovely autumn afternoon. Holidays are always welcome and provide a welcome balance in my life between

work and home. Tomorrow we are off to Yamba to enjoy some beach time and relax some more.

As the PCA Conference in Perth comes closer, PCQ Council is enthusiastically planning for our own conference in 2010 in Ipswich and then the next PCA Conference in Cairns in 2011. Don't forget to register for the Perth conference now to make use of the group discount. In order to reach as many people as possible please inform us if you have any local events to add to the newsletter or place on the website.

The gloomy economical situation has stretched its tentacles into health care. With increasing government spending to create jobs and infrastructure, there are less and less funds available to consider growth areas. Our ageing population and the influx of people into Queensland are having a significant impact of provision of palliative care from the generalist level / primary care up to specialist level services. The number of people requiring care and the

associated demands keep rising without a corresponding rise in service capacity. The government's capacity to provide increased funding appears limited. The recent 'crisis' one-off payments to non-government providers in Queensland were certainly welcome but will not solve the long term problems looming for quality end of life care in this state.

The palliative care sector in Queensland needs to work hard together to best weather this growing issue. PCQ is hosting the inaugural End Of Life Alliance meeting in National Palliative Care Week in Brisbane. Important stakeholders have been invited including a representative from Queensland health. We hope to foster and support a network of people who are interested in working towards real solutions. At the very least we need to maintain best end of life care provision, to encourage all providers to work collaboratively, look at novel ways to work together, and gather information from other groups nationally and internationally.

The PCA Council meets in mid June with myself and Carol Hope attending as delegates for PCQ. PCA continues to support us (PCQ) with advice about approaching government departments and John-Paul has already arranged meetings to advise fund holders, policy branch and planning branch about the issues facing palliative care provision in Queensland. We will continue regular meetings with Queensland Health as part of our advocacy role. It is the noisy wheel that gets oiled!

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I would like to take this opportunity to ask all members to be active in their work and community about increasing awareness of the importance of quality end of life care regardless of geography, ethnicity, financial status or place of care. Encourage colleagues to talk about their experiences with death and dying, promote educational activities and joining PCQ. Be part of the group working to make Queensland the best place in Australia to die.

Dr Louise Welch
President

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Executive Manager's Report

The last two months have been a very busy period for PCQ, and after receiving valuable feedback from our members, I am now confident that we are once again successfully functioning as the peak representative body for palliative care and end-of-life care in Queensland.



ADVOCACY ISSUES – QLD NON-GOVERNMENT PALLIATIVE CARE NETWORK

In March this year, PCQ was approached by six of the seven non-government providers of palliative care to represent them at Queensland Health level as part of a formal move to secure an increase to recurrent service agreement funding. Generally, for the last three contract terms, service agreement funding to non-government providers has increased by the CPI only. Despite a small number of emergency exceptional payments over the years, Queensland Health has not provided growth funding to the NGOs, despite the fact that operational expenses have increased, service demand has increased and the administrative costs associated with ongoing quality assurance and accreditation have also grown.

In keeping with this request for representation, PCQ met with Professor Andrew Wilson, Deputy Director of Policy Planning and Development, to discuss the current financial crisis facing the NGOs. PCQ made Professor Wilson aware of the current issues facing NGOs, including the reduced capacity of NGOs to attract the charity dollar, given the current global financial crisis. Professor Wilson was not able to commit to an increase in service agreement funding to the NGOs, but did agree to attend and participate in the End-of-Life Alliance meeting on May 27th.

Although PCQ was unable to secure an agreement to increase contract funding to the NGOs, there have been two significant successes.

Firstly, we have seen the development of the 'Queensland Non-Government Palliative Care Network', a consortium that comprises six of the eight non-government palliative care providers. This consortium has the capacity to provide one unified voice for non-government providers, and as such has the potential to have a far greater impact in terms of lobbying and advocacy. It will also provide a valuable platform to support the exchange of information between NGOs, and support operational and strategic collaboration.

Secondly, the fact that Queensland Health is now prepared to work closely with PCQ to resolve current issues within the sector, can be seen as a major victory. It may also be viewed as one small step towards the development of a broader statewide plan for palliative care in Queensland, a plan that would acknowledge and address critical issues within the sector, including workforce sustainability and resource shortfalls.

LAUNCH OF THE UNDERSTANDING PALLIATIVE CARE DVD

As we approach National Palliative Care Awareness Week 2009 (24-30 May), it is a good time to reflect upon the general public's awareness of palliative care and end-of-life care more broadly. As the peak representative body for palliative care and end-of-life care in Queensland, PCQ's principle responsibility is to raise awareness of end-of-life issues in the community, and to raise the profile of palliative care in Queensland. This is a challenging task given the limited resources available to PCQ, and the general public's reluctance to engage in conversations that focus on death or dying. For this reason, we have developed the 'Understanding Palliative Care' DVD, a thirty-five minute education DVD that provides an overview of palliative care, end-of-life issues, and the palliative care process in Queensland. We hope that this professionally presented educational DVD may provide a valuable tool for raising awareness

within the general community, whilst concurrently providing patient, family and health professionals with a valuable tool to support quality end-of-life care.

The DVD will be launched by television personality Marie-Louise Theile, on Wednesday May 27th as part of National Palliative Care Awareness Week 2009. It will be made available in two editions; a national edition and a Queensland edition, the latter providing an additional five minute overview of both the Palliative Care Information Service (PCIS) and PCQ. The Queensland edition is most suitable for individuals and organisations living or operating in Queensland, and the national edition for those living or operating either interstate or overseas. It will also be available in either a standard DVD boxed version or a shrink wrapped cardboard sleeve version.

The sleeved version of the Queensland DVD will be provided free of charge upon request to all individuals in Queensland affected by terminal illness, however it is a requirement that they contact PCQ directly on **(07) 3633 0096** to obtain their free copy. The Queensland edition of the DVD is also available for free download from the PCQ website (www.palliativecareqld.org.au) and the national edition available as a download from 'You-Tube'.

Due to the significant costs associated with duplication, distribution and updating of the DVD, PCQ has decided to charge a fee to individuals requesting the more expensive boxed edition of the DVD (\$15 plus P & H), or to non member organisations requesting either individual or bulk orders of either the boxed or sleeved version (\$3 plus P & H) of the DVD. More information about the costs associated with the DVD is available from the PCQ website.

It is our hope that the Understanding Palliative Care DVD can be watched by everyone who has an interest in palliative care or end-of-life care, including patients, family members, carers, health professionals, members of the general community and even people in the workplace. We hope that the DVD can also be shown in schools and educational facilities, residential aged care facilities, support groups, community based organisations and in the corporate sector.

Wherever possible we would also encourage members of PCQ to promote the use of the DVD in all settings, not only to raise awareness of palliative care and end-of-life care but to raise the profile of PCQ itself. In these uncertain times, when government funded dollars are becoming more and more difficult to access, it is important for PCQ to maintain an alternative yet viable income stream, and to encourage the sustainability of our own organisation.

IF ONLY I KNEW – A NATIONAL COMMUNITY INITIATIVE BY PALLIATIVE CARE AUSTRALIA (PCA)

As part of National Palliative Care Awareness Week 2009, PCA has developed an innovative community awareness initiative titled, 'If Only I Knew'. The aim of the campaign is to assist people to find the answers they need when confronted with dying, death or loss. The initiative will be officially launched at Parliament House in Canberra on May 27th. To order your 'If Only I Knew' resources, please contact PCA directly on **(02) 6260 2770** or visit the PCA website, www.palliativecare.org.au.

NEW PCQ VICE-PRESIDENT

Finally, PCQ is pleased to announce the appointment of Carol Hope, Palliative Care Clinical Manager, Mount Olivet Hospital to the position of PCQ Vice-President. Carol brings a wealth of both operational management and clinical experience to the position, and as an organisation, we look forward to benefitting from her knowledge and passion, particularly in relation to strategic planning within the palliative care sector. Welcome Carol!

Please remember that if you require any further information about your membership, or you would like to comment or make suggestions in relation to the strategic direction of the organisation or palliative care in Queensland more broadly, your input is always welcome. Please feel free to contact me directly at any time on **(07) 3633 0096** or j.kristensen@palliativecareqld.org.au.

John-Paul Kristensen
Executive Manager

Caring For the Whole Person

This article is adapted from a Workshop led by Dr. Ian Mavor at the International Congress on Care of the Terminally Ill, in Montreal.

As the management of pain is so central to palliative care, an analysis of the potential sources of pain can make a valuable contribution. Because all pain is experienced in the body, there may be a tendency to focus on the body symptoms as the cause of the pain. This can result in a failure to take account of a range of other factors that have contributed to the onset of the pain and which may reduce the effectiveness of the medications used.

Dame Cicely Saunders, who was committed to caring for the whole person, body, mind and spirit, referred to the comments of one of her patients, "When you listened to me, the pain got less." This indicates that factors were at work beyond the simple administration of medication, and highlighted the vital role of interpersonal relationships in the care process.

In analysing sources of pain, I find it helpful to think in terms of dimensions of human functioning. For this purpose, the traditional categories of body, mind and spirit can be further analysed.

The body can be thought of as including physical functioning and also the emotional. While feelings are often linked primarily with brain activity, they are experienced throughout the body as endorphins and other chemicals take effect. The multiple physical effects of the flight and fight response, in regard functions such as breathing, heart rate, digestion, blood pressure and muscle tone, is a good example of this process. Similarly, the emotions associated with the grief process have major physical effects.

It is well recognised that broken relationships can result in heartache, and that this is different from having a heart attack. In the long run, however, unresolved relationship issues can have an impact on the functioning of

the heart and can contribute to physical symptoms.

In regard to the mind, both mental and moral functioning can be considered, while spirit can be analysed in terms of spiritual and aesthetic dimensions.

Beyond the individual level, pain may also be influenced by social and environmental factors. The social dimension acknowledges that human beings live in interpersonal contexts and that the processes of socialisation shape our consciousness. These also shape individual functioning, e.g. our mental processes depend on the use of language and our moral sensitivities are shaped by social norms. In addition, the environmental dimension acknowledges our participation in a wider network of living and non-living entities.

THE CONCEPT OF ENERGY FLOW

One approach to the analysis of human functioning uses the concept of energy flow within the body and beyond the individual level. Arnold Mindell, founder of Process Oriented Psychology, also known as Process Work, drew on his knowledge of physics and Jungian psychology to refer to the energy dynamics of the body and relationship as a form of "dreaming," using the term "dreambody." Similar concepts can be found in some forms of oriental medicine.

In this approach, the energies in a healthy body are flowing freely, whereas blocked energies become associated with symptoms. This can result in loss of function and consequent pain.

For pain management to be effective, attention can be given to the impact of these various dimensions of human functioning. By identifying these areas of functioning, it is possible to work on freeing the flow of energy in each dimension.

This also places an emphasis on the importance of having a multi-disciplinary team involved in palliative care, as different skills may be required to deal with each of the dimensions.

THE EIGHT DIMENSIONS

Physical - living with awareness and acceptance within the body, including: physiological functioning and symptoms; diet and nutrition; physical abilities and disabilities; mind-body connections; leisure, exercise and recreation.

Free energy: the body functions strongly, moves with grace, plays well, exercises freely and feels fit.

Blocked energy: feel weak, unable to compete, unskilled, dealing with illness or disability.

Emotional - dealing with various moods, feelings and attachments, including: the range of human feelings/ emotions; physiological states and emotions; flight and fight reactions; response to challenge and risk; processes of grief and bereavement.

Free energy: feel good, in control, express strong grief, able to identify and express feelings.

Blocked energy: overwhelmed, constantly stressed, out of control, cannot stop crying, overcome by anger.

Mental - finding meaning and purpose in thoughts, beliefs and understandings about one's self and the world, including: forms of knowledge, with knowledge of self; left/right brain functions; conscious and unconscious states of mind; systems of belief and attitudes; sense of past and future.

Free energy: think clearly, know a required skill, learn something new, have insights.

Blocked energy: unable to think clearly, get information wrong and feel ignorant.

Moral - making decisions about right and wrong, and dealing with failure, including: conscience and guilt; ethical principles and values; challenge and risk taking with awareness; sincerity and fairness; judgment of feelings as 'positive' or 'negative'.

Free energy: stand up for a principle, feel right about a hard decision and take responsibility.

Blocked energy: unsure of what to do, blame others, act to harm self and others, addictive.

Spiritual - seeking to transcend the here and now, dealing with ultimate questions about personal worth, power, hope and mystery, searching for altered states of awareness, including: self-awareness, self-esteem and identity; meaning, purpose and commitment; interconnectedness with people and things - past, present and future.

Free energy: inner energies flow, able to be alone yet feel connected, life has meaning and purpose, able to face and deal with problems.

Blocked energy: fear being alone, cut off from others and higher power, lack meaning or purpose, unmotivated, give up.

Aesthetic - giving expression to the inner sense of beauty, including: sense of balance and wholeness; perceptions of beauty and quality; self-expression and artistry; access to intuitive abilities; capacity for fun and play.

Free energy: act with balance and harmony, being artistic, in tune with surroundings, move and work gracefully, enjoy beautiful sights, sounds, smells, tastes, touches.

Blocked energy: awkward, clumsy, discordant, feel ugly or repulsive.

Social - handling diverse relationships, including: belonging to social groups; forms of friendship and partnership; experiences of alienation or aloneness; nuclear and extended families, peer groupings; communities of belief; and societies and cultures.

Free energy: relate well to others, feel accepted, contribute to teams, committed in relationships, enjoy humour and provide leadership.

Blocked energy: unable to relate to others, feel rejected, embarrassed or laughed at.

Environmental - relating to the natural world, including: a sense of being part of the wider world; belonging to the natural order; links to physical surroundings; respect for living and non-living things; a sense of relatedness to nature; feeling part of the cosmos.

Free energy: a sense of connection with the environment, owning one's place in the natural world, compassion for all sensate beings.

Blocked energy: a sense of separation from the environment and the natural order, lack of respect shown by regarding nature as simply something to control and use for human purposes.

FUNCTIONING AS A WHOLE PERSON

There is no suggestion that palliative care can heal all the dysfunctional aspects of a person's life, some of which have taken years to establish. It may be possible however, to consider ways in which even small changes can contribute to the overall care of the person. Attention to the spiritual and aesthetic dimensions can often assist in resolving the split between mind and body that is present in many people. This split is sometimes reflected in the mind's battle against the disease process where the body is seen as the problem. The body is dying and the mind is resisting. The split is particularly strong when the illness results from a failure of body functioning, rather than having an identified external cause. At other times, the split is reversed, in that the mind has decided to stop struggling but the body is not yet ready to die. This is reflected in calls for people to be able to give the body an injection when the mind has decided it is time to go.

As palliative care attends to the whole person, it can help ease this conflict through recognition of the various dimensions and helping bring them into harmony. This helps the person find the sense of acceptance that Elisabeth Kubler-Ross described so well, and prepares them for a "good" death in the best sense of that word.

***Rev Dr Ian Mavor**
Director Hopewell Hospice
PCQ State Council Member*

Life Reflections: A Patient Biography Service

" I was trying to put myself in a bottle that would one day wash up on the beach for my children.....none of this is a replacement for a living parent... it's about doing the best you can with limited resources" Randy Pausch, The Last Lecture, 2008.

It was a very similar sentiment that stimulated me to embark upon undertaking my first life journal with a patient referred to me at the Princess Alexandra Hospital. It was the very positive feedback from that first journal that led to the above project. This project was funded by Allied Health Cancer Care Research (2007) with the aim of reducing the emotional distress patients and families experienced at the end of life via the provision of a confidential biography service, thus enabling the person to reflect upon their life and legacy.

BACKGROUND

I had been interested in this work following an inspiring presentation by Teomanga Hospice (NZ) at a Palliative Care conference in Adelaide 2003, however there had never been an appropriate time to explore this as a therapeutic intervention.

In April 2007, I was approached by the wife of a patient to help her husband document his life story. She was totally committed to ensuring that her husband should be given every opportunity to leave a written legacy for their two small sons aged two and ten months. It is very clear to me none of this would have happened without the tenacity and determination of this amazing woman. When I met her she was desperate and time was running out. So began a race against time.

In one day, the patient was interviewed as was his wife, mother and sister. His wife provided photos, and within twenty four hours a life journal was written, photos scanned and with the aid of Medical Illustration Department of the PAH, a bound copy of the patients story was given to his wife. She read the journal to her husband and he died the following day. Feedback from the family both in the short term and the months ahead confirmed that the journal was very beneficial.

His widow was very keen to ensure that other patients and their families should be able to access this assistance and this provided the impetus for the study to determine if the intervention was helpful to other patients and carers.

IMPLEMENTATION

Patients for this study were identified by Brisbane South Palliative Care clinical team with criteria of being over eighteen years of age, competent to consent, less

than three months predicted survival and English speaking. The interviews were taped, transcribed and the patient was given a draft for vetting. There was pre and post evaluation as well as carer contact following the death.

Patients were interviewed either in their home or hospice. Interestingly no patients were seen at the tertiary centre. There were three common themes identified by the patients for the reasons for undertaking a life journal:

- a desire to leave something behind for family and friends;
- a need to address some life issues, and
- desire to participate to help others.

One patient also noted that she thought it would be very helpful to her family to organize her funeral, as they did not know a lot about her early life and what was important to her.

EVALUATION

The patients gave very positive evaluations about the journal itself, and many were astounded at how meaningful their life story was when translated into the written word. A good story equalled a good life, and it was indeed very rewarding to see the extraordinary impact on a number of patients. In a very real sense it gave their life a sense of meaning.

The journals were as unique as the people whose life story's they told. They varied in length from ten pages to over sixty pages. Some were very rich with photos and memorabilia, but others were not. One patient, who will always remain for me as someone who really benefited from the journal, was a man for whom life had not treated well. He had no family, never married and was significantly socially isolated, but in the latter part of illness he had been cared for by a kind and wonderful lady.

When he was first asked if he wanted to do a journal, he did not think he had a story to tell. He had no photos and as it transpired he had never had a photo taken of himself. That was very soon rectified. The journal provided an opportunity for him to reflect upon what had been essentially a tough life, but also one where there had also been riches. Via the journal in particular, he was able to express his gratitude to his carer, as he felt blessed to have found her in his time of need. Significantly his completed journal was on his coffin and

his story was told at his funeral.

Other comments from carers suggest that the life journal was of great benefit in facilitating improved communication within the family and also between the patient and the treating team.

One wife described the writing process as "a healing journey and his story has left something powerful for our children".

For others, it became a means of documenting important family history:

"With only months to live and with Mum being the last of her siblings, we were conscious that we needed to preserve her story.... The assistance proved invaluable in helping Mum to express and record the more difficult times in her life which previously she had found hard to do.... Mum's fully story is now told... we will treasure her experiences and thoughts as recorded for us"

For some it provided ongoing comfort following a difficult palliative journey:

"When Dad first died, all I could remember was the awful pain he had been in the weeks before he died... I hated that memory... however the journal helped so much It reminds me he had a life before he got sick and it was a full and happy one.... I often turn to the journal when I am feeling down. It has also helped my young sons. I had not realized how attached they were to their granddad, they often look at his story"

CHALLENGES

There were certainly some significant challenges in undertaking this project. The patient's declining health meant that flexibility was paramount. Some journals simply could not be completed due to declining physical health and cognitive capacity. The psychological mind set was very important. In one situation, the patient did not fully embrace that his condition was palliative and the impetus to do the journal had largely come from his wife. He decided not to complete his journal. Like any intervention, it is helpful for some and not for others. It is also a highly labour intensive process.

Since completing the project, I have reflected upon what I consider to be the real impact of the project, and I remain very positive about the benefits. Baz Lurman was quoted in the Courier Mail following the release of 'Australia'. "You

cannot really possess anything; not land; not a person; not a child...all that you can possess in the end of life is your story". It was an enriching and humbling process.

FUTURE DIRECTIONS

Future directions are unclear at this stage, however I am aware of the great interest in this field of work, and have been advised that a number of palliative care services are undertaking similar work. Some patients suggested that a carer journal would be very useful. Questions also remain as to why some patients accessed the process and others did not.

I continue to utilize life journals for selective patients but this is limited by resources. I believe that the most appropriate and efficient model of care could be based on trained volunteers. The work is very challenging however and in my experience, the journey itself is as important as the end product, and staff undertaking this work need to have access to skilled supervision and support.

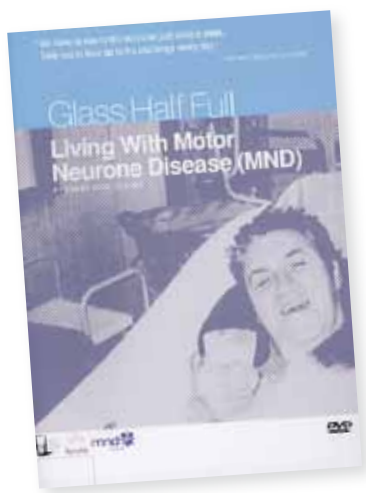
I believe it is an area of great potential and I am in full agreement with Dr Rachel Remen when she says that "A good story is like a compass and points to something unchanging and allows us to set our direction by it. Sometimes we need a story more than food to live well."

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Glass Half Full: Living With Motor Neurone Disease (MND)

In mid 2008, Camille Doyle and Shyla Bower from Karuna Hospice Services submitted a grant application to Motor Neurone Disease Australia for some funding to create a supportive, inspiring and educational DVD resource presenting a unique individual's experience of Motor Neurone Disease (MND). The resource was intended to be a twenty-eight minute documentary-

style film, featuring a client and family of Karuna Hospice Service, who had formally agreed to participate in the project. Subsequent to this grant application, MNDA agreed to fund the project with support from its state affiliates. With this generous support, and that of many big-hearted individuals who gave their expertise, time and efforts to the project itself, we are pleased to announce that the DVD, 'Glass Half Full', is now available through Mandala Books.



This documentary provides a rare insight into an inspiring person's life, as well as that of his family, his support team and ultimately his disease. He openly invites you into his home and shares his journey with honesty and humour. Tony and Dot's story is about experiencing life with a positive approach, no matter what comes your way. Tony and his wife Dot, lived in suburban Brisbane, and spent their time working in the airline industry, travelling the world and raising a family. Then Tony was diagnosed with MND, a rare disease which affects approximately 1 in 15,000 Australians. Although initially they struggled to come to terms with the diagnosis and palliative prognosis, they chose to 'add life to years', rather 'than years to life'.

The DVD provides a rare insight into experiencing life with a positive approach, no matter what comes your way. It will inspire you to hug your children more, tie up loose ends, reflect on all you have and most of all, look at life with a 'glass half full' attitude."

The DVD is aimed at health professionals, those living with MND, their families, friends and the general public. It is hoped that the DVD can demonstrate the

potential to maintain a meaningful quality of life for an individual living with MND, through the implementation of early (appropriate) referral to a palliative care service and the subsequent involvement of inter-disciplinary specialist services to support and minimise the impacts of the gradual progression of this potentially debilitating disease.

Glass Half Full: Living with Motor Neurone Disease can now be purchased through Mandala Books (www.mandalabooks.com.au) at a cost of \$15.00. For more information, please call (07) 3632 8380 or email info@mandalabooks.com.au

Federal Budget 2009-10 – What Does it Mean for the Palliative Care Sector?

Palliative Care Australia (PCA) is pleased that despite the threat of an unprecedented tight budget, palliative care does feature well and has been given a level of priority in the second Rudd Government budget. Palliative care has received strong recognition both through direct funding and through the opportunities for stronger integration within aged care, primary care, workforce development and pharmaceuticals.

Overall the health budget has few surprises, the big ticket 'new money spend' items were leaked last week, with \$1.3 billion over six years to improve cancer infrastructure, extra funding for residential aged care, and an undisclosed amount to support the establishment of the national workforce agency. On the flip side the big ticket 'money savings' include reducing the private health insurance rebate.

Congratulations go to the selected projects under the current National Palliative Care Program, that are to receive ongoing funding (pending funding agreement). A total of \$14.4 million has been secured into this national program from previous Australian Health Care Agreement allocations.

The Australian Government, together with all state and territory governments, now commit to the revision of the National

Palliative Care Strategy, in recognition of emerging health reform policies and meeting the challenges of palliative and end-of-life care integration across the health system. Palliative Care Australia continues to meet with senior officers within the Department of Health and Ageing to better understand the impact of this budget, and to help shape the key investments into palliative and end-of-life care. The questions PCA will be seeking clarification from the department at the scheduled post-budget meeting include:

- How can PCA ensure palliative care is well integrated across the new investments in workforce, primary care and aged care?
- Do the models for the new integrated cancer centres intend to fully integrate palliative care?
- How will the existing National Palliative Care Program projects be evaluated, prior to ongoing commitment?
- What are the plans for revising the National Palliative Care Strategy?
- Has the proposed model for advance care planning programs across residential aged care facilities been fully evaluated in terms of impact on the specialist palliative care sector?

While there is a lot for us all to do to realise some of these opportunities, we are confident that the understanding of, and support for palliative care, is growing within our partnership with government. This is the work that PCA, together with our members working at their respective state and territory jurisdictions are striving to achieve.

Donna Daniell
Chief Executive Officer
Palliative Care Australia

Key measures for palliative care. National Palliative Care Strategy

In 2009-10, the Department, in collaboration with state and territory governments, subject to ministerial agreement, will start to update the National Palliative Care Strategy, to include the emerging health reform policies and

meet the challenges of palliative and end-of-life care integration across the health system. Relevant stakeholders to be consulted in this process include state and territory governments, Palliative Care Australia, other sector stakeholders and leading academic and clinical palliative care experts.

PALLIATIVE CARE AND COMMUNITY ASSISTANCE

The Government aims to promote better planning, delivery, and coordination of health services and develop and support an integrated palliative care system. The Budget paper states, "The Department works with state and territory government departments, consumer representatives like Palliative Care Australia and specialist palliative care services to deliver a range of projects. These projects aim to build palliative care expertise in health and other care providers, and to improve consumers' knowledge of the services available to them".

ACCESS TO QUALITY PALLIATIVE CARE

In 2009-10, the department will continue workplace initiatives such as the Program of Experience in the Palliative Approach (PEPA) which provides palliative care workplace training and workshops for health, aged and community care professionals. The department will also support the inclusion of palliative care education (PPC4U) as an integral part of medical, nursing, and allied health undergraduate training, and ongoing professional development.

ACCESS TO PALLIATIVE CARE MEDICINES

Many Australians requiring palliative care choose to be cared for and die at home. A priority for the Australian Government is to ensure that this significant population has access to, and quality use of, palliative care medicines. The department has included dedicated palliative care listings in the Pharmaceutical Benefits Scheme (PBS) in 2009-10. These listings allow a greater number of palliative care patients in the community to access the medicines at a more affordable cost. In addition, up to five trials of the

use of palliative care medicines in the community will be held in 2009-10.

AGED CARE

In 2009-10, the department will introduce guidelines for the provision of palliative care in community settings to complement those already developed for use in residential settings.

Also included are:

- increased government subsidies to help residential aged care services to operate viably in areas where it is difficult to do so, including in regional, rural and remote Australia
- funding for an improved national approach to quality palliative care
- continuation of the successful transition care program, helping older Australians return to the independence of their homes after a hospital stay.

PALLIATIVE CARE RESEARCH

The Australian Government aims to improve palliative care by encouraging research into delivering palliative care, improving access to palliative care knowledge by all health professionals and fostering clinical research into medicines. The Department and the National Health and Medical Research Council collaborate to fund research activities through the Palliative Care Research Program. This program will develop capacity within the palliative care research community.

ADVANCE CARE PLANNING

In line with the reform directions in the 'Caring for People at the End of Life' chapter in the National Health and Hospitals Reform Commission's A Healthier Future for all Australians – Interim Report December 2008, the department will work to promote the adoption of advance care planning in residential aged care facilities. In 2009-10, the department will build on the projects it currently funds to increase the use of advance care planning.

POTENTIAL INDIRECT FUNDING FOR PALLIATIVE CARE WORKFORCE

The budget workforce initiatives are claimed to provide \$500 million to support the expansion of pre-professional clinical training places by 2013, including:

- \$148 million over 5 years for an additional 75 GP training places in 2009, 100 in 2010
- 22 Remote and Vocational Training Scheme GP training places from 2010
- \$41m over 5 years for prevocational training for doctors in general practice.

While there is some funding reduction for General Practice Education and Training Ltd, the overall funding increase for prevocational training for GPs is welcome. The number of general practice training places will increase to over 800 in 2011. These could be available for palliative and end of life education and training.

PROVIDING ACCESS TO MBS AND PBS FOR NURSE PRACTITIONERS

\$59.7 million over four years to provide access to MBS and PBS for nurse practitioners. Nurse practitioners play a very important role in the provision of quality care at the end of life.

NEW MEDICARE ITEMS

These new Medicare items will encourage GPs to undertake extra mental health skills training, and requirements for treatment plans will be revised to ensure that patients receive high quality care appropriate to their needs. There will also be mandatory CPD requirements for general psychologists, appropriately trained social workers and occupational therapists providing psychological services under Medicare.

From our perspective, training in grief and bereavement and care for patients and families involved in palliative care should be included in skills training and continuing professional education. PCA will need to work in the future on Medicare item numbers for palliative medicine consultations.

RURAL HEALTH WORKFORCE

There is \$134.4 million over 4 years for the Rural Health Workforce Strategy, and \$10.9 million over 4 years to maintain rural multidisciplinary training. This provides opportunities to enhance the integration of care services in rural and remote locations to include quality care at the end of life.

NATIONAL PARTNERSHIP AGREEMENT ON HOSPITAL AND HEALTH WORKFORCE REFORM

The Australian Government is working with the states and territories on key reforms to the health and hospital system through the Hospital and Health Workforce Reform National Partnership, to better coordinate and expand capacity for clinical training across a range of workforce settings, and assist with workforce planning.

SUBACUTE

The budget provides \$500 million to the states and territories in 2008-09 to deliver improved subacute care services, including palliative care, which will enable many people to leave hospital for care in the community. Funding will be provided to expand service provision levels by 5% annually over the period 2009-10 to 2012-13 in each state and territory, and to better address regional availability. In 2009-10 and future years, the department will work with the states and territories to implement this initiative, including developing data and facilitating publication of subacute care performance against targets.

CANCER CARE

Several announcements have been made in cancer care.

- \$1.3 billion over six years in improving cancer infrastructure:
- two integrated cancer centres (Sydney and Melbourne)
- up to ten best-practice regional cancer centres and associated accommodation centres
- Building Cancer Support Networks Program
- Cancer Services Network National Demonstration Program
- improvements to lung cancer care
- National Cancer Monitoring Centre

- subsidised access to cancer medicines:
 - Avastin – added to PBS – for metastatic bowel cancer
 - Sutent – added to the PBS – for renal cell carcinoma (kidney cancer)
 - Herceptin – outside PBS – treatment for metastatic breast cancer.

CARERS

The increase in the age pension has also provided additional support for carers through the Carer Payment. As a result of the changes, carers will receive an additional \$32.49 per week for the single payment (if they are on the full rate), and couples will receive an additional \$10.14 per week if they are on the full rate. This brings the weekly single rate to \$336.68, and the weekly rate for couples to \$507.50. In addition to this, carers who receive the Carer Payment will now annually receive a \$600 payment called the Carer Supplement. If a carer receives both the Carer Payment and the separate Carer Allowance, they will be eligible for two Carer Supplement payments, bringing the total to \$1200.

INDIGENOUS INITIATIVE

The budget also provides funding for the Divisions of General Practice to employ 80 full-time equivalent indigenous outreach workers as well as 80 full-time equivalent project officers to support the outreach workers. These positions will encourage greater use of primary health care services by Aboriginal and Torres Strait Islander peoples and improve the cultural safety of primary health care services for Indigenous Australians. According to the budget information this initiative is based on international best practice, but will allow flexibility for local needs and contexts.

DIVISIONS OF GENERAL PRACTICE

The Department of Health and Ageing has also developed a new funding formula for the Divisions of General Practice delivering an additional \$7.6m over 5 years. The network will be funded through an updated formula which better reflects changes in individual division demographics, such as population size (weighted by age, gender, socio-economic and Indigenous

status) and rural locations. The new formula will mean a boost in funding for some divisions, particularly where there has been significant population growth or other demographic changes. However, because this would mean that some divisions would end up receiving less funding, the government has committed to fund these divisions at their current level until 2012.

FURTHER INFORMATION

Details can be found in Budget Related Paper 1.10 –Health and Ageing portfolio, at www.health.gov.au. Search for “palliative”.

Member Update

MEMBERSHIPS RENEWALS

Membership renewals are due again on June 1st 2009, and this year, it is our hope at PCQ that members will be able to pay their membership subscriptions on-line at the PCQ website. Over the last three months, PCQ has been working closely with PCA to develop the PCA Connect Database to a point where it can also be used by state member organisations to house individual membership databases. This would mean that all of the state organisations will eventually pay a small fee to share the one customer relationship management (CRM) system, each having their own portion of the database to store member information. As a long term plan, this will enable member organisations to reduce costs and to improve the overall functionality of membership databases.

We will soon be forwarding a letter to all PCQ members outlining the process for renewing memberships. In the meantime however, please bear with us while we work towards developing a more effective and efficient solution for the payment of membership subscriptions. For further information, please contact PCQ.

CHANGE OF POLICY REGARDING THE SUPPLY OF PCQ RESOURCES

As mentioned in previous correspondence, from July 1st 2009, PCQ will be charging a small fee for

bulk orders of its resource materials, including fact sheets and brochures. The fee will only be charged to organisations requesting bulk orders, however individuals or members of the general public who request resource materials will continue to receive them at no charge. After July 1st, bulk orders of resource materials will be accompanied by an invoice from PCQ, for the cost of both resources and postage and handling.

Developing, reviewing and printing resource material is a very expensive process, and it is for this reason that PCQ has decided to request a payment for bulk orders of resource material. This policy change should encourage organisations to download information and fact sheets directly from the PCQ website, or to limit the numbers of fact sheets according to need. Wherever possible, we would ask that members and organisations order only what they need, ensuring that they receive only the most current version of PCQ fact sheets and resource materials.

PCQ LEASE UPDATE

Following months of negotiation and consultation, PCQ has signed a co-tenancy agreement with the Queensland Aged and Disability Advocacy, ensuring that PCQ will permanently remain at its current address in Copperfield Street Geebung. Over the last six months, PCQ reviewed a number of alternative housing arrangements, options and locations for the PCQ offices, however it was decided by State Council that the current address, rental conditions and arrangements were adequate and appropriate. The lease is an ongoing arrangement, with either party required to provide ninety days notice if there is an intent to discontinue the lease.

PCQ OFFICE HOURS

The office at PCQ remains officially staffed between 10.00am and 4.00pm, Monday, Wednesday and Friday. Although we may be in the office at other times throughout the week, we can only ensure that the phone is answered during these times. If you do call outside of these hours, please leave a message on the PCQ voicemail, and we will endeavour to return your call during our office hours.

SECOND TELEPHONE LINE INSTALLED AT PCQ

Please be advised that PCQ has recently installed a second telephone line at the Geebung office. There have been a number of concerns raised recently by members over calls not being answered, or calls being diverted to answering machines, despite the fact that staff have been in attendance. With two lines, it will now be possible to answer two incoming calls simultaneously, avoiding the need for callers to leave messages in some instances.

STAFF CHANGES

Please note that there have been some staff changes at PCQ. We welcome Maria Mitchell on to our team in the position of Administration Officer. Maria's principle function is to manage the PCQ books, including accounts payable and receivable, wages, reconciliations and also some general administration. Maria will be working Thursdays from 9.00am to 5.00pm and Friday from 8.00am to 4.00pm.

Administration Assistant Cathy Boga continues in her role, but has changed her hours to Monday and Wednesday from 10.00am to 4.00pm. Apart from providing general administrative assistance, Cathy's roles include resource distribution and membership.

Sunshine Coast Branch Update

The Sunshine Coast Branch of Palliative Care Queensland meets second monthly at The Sunshine Coast Private Hospital, Syd Lingard Drive, Buderim.

Our meetings start with drinks and nibbles at 5.30 pm, and invited presenters commencing their presentations from 6.00pm. Our next meeting will be held on June 1st.

Our membership numbers are increasing and we cater to approximately 40 attendees at each meeting, with some members travelling from as far as Kilcoy and Redcliffe.

Our focus at Branch level is to increase the awareness of palliative care and end-of-life care on the Sunshine Coast by providing education, support and assistance to all personnel working in this specialized area.

All interested persons or health professionals are invited to attend our branch meetings, with membership applications available at the door for interested persons. This is a great networking opportunity.

For more information, please contact Denise Simmons, Sunshine Coast Branch Coordinator on **0400 646 027** or **d.simmons@palliativecareqld.org.au**.

Member Profile

Marg Cook – Clinical Nurse



My interest in palliative care began many years ago after seeing many people die lonely deaths hidden behind curtains at the end of the

ward, protected from the truth by loving families and caring health professionals. Their pain was often not recognised and poorly managed.

I have been a member of Palliative Care Queensland since its inception and have been on many committees with some very enthusiastic and dedicated people developing medication guidelines, standardising documentation and streamlining referral processes between hospital and community based organisations.

My palliative care career began when I received sponsorship from Blue Care for the Hospice/Palliative Care Course at Mount Olivet Hospital and on completion was appointed Palliative Care Resource Nurse (Brisbane Central) in 1990 seeing first hand not only the rewards of caring for someone with a terminal illness at home, but also the difficulties. I became acutely aware of the level of knowledge

required to provide palliative care in the community and spent the next ten years increasing my clinical skills at Mount Olivet, Canossa and Prince Charles and completed a graduate diploma in Palliative Care at the Australian Catholic University.

During this time, I also developed an interest in the management of wounds affecting people with advanced disease, such as malignant wounds and lymphorrhoea (leakage of lymph fluid) and completed the Master in Clinical Nursing (Wound Management) at Central Queensland University. I was also fortunate to be able to be involved in palliative wound management education programs at Mount Olivet, Blue Care, St Luke's and in country areas.

Following my graduation, I returned to my first love of caring for people in their own homes with Karuna Hospice Service, Silver Chain Home Hospice Service in Perth and am currently on a six month contract with RDNS (Focus) in Adelaide.

Events

MEETINGS

Brisbane North Palliative Care Forum

Information and networking meeting for individuals working in palliative care and end-of-life care. No set agenda. Afternoon tea provided. All welcome.

2.30pm Monday May 25th, Karuna Hospice Service, Cartwright Street Windsor

Palliative Care Network Meeting

An informal meeting for clinicians and others who work in the area of palliative care and end-of-life care in Brisbane. The group meet bimonthly for breakfast, networking and to share information about clinical and other relevant issues. Clinical focus, all welcome.

7.15am Tuesday May 26th, Coffee Club, Brunswick Street Fortitude Valley

EDUCATIONAL EVENTS

Mt Olivet Hospital, Palliative Care Education Program

- **22nd May 2009-Managing Lymphoedema in the Palliative Care Environment - \$180**
- **10th July 2009-Palliative Care Perspective for the Volunteer-No charge**
- **22nd July 2009-Grief in the Family-\$180**
- **30th & 31st July-Principles & Practices of Palliative Care for AINs & PCAs-\$350**

For more information, please call Mount Olivet Hospital **(07) 3240 1111**

Centre for Palliative Care Research and Education (CPCRE) 8th Annual Research Conference: Palliative Care in the Community - June 5th 2009

The CPCRE 8th Annual Research Conference is being held at the Education Centre Auditorium at Royal Brisbane and Women's Hospital on Friday 5th June 2009.

The conference theme is 'Palliative Care in the Community'. The conference will showcase various palliative care research activities in general practice, community care and aged care.

The national keynote speaker is Prof Margaret O'Connor, President of Palliative Care Australia and our local key note presenters are Dr John Rosenberg, A/Prof Geoff Mitchell and A/Prof Deborah Parker.

Registration forms (including payment details) and the conference program are available on the CPCRE website: http://www.health.qld.gov.au/cpcpre/rsrch_conf_09.asp. For further information please phone **(07) 3636 1449** or email cpcpre@health.qld.gov.au

Program of Experience in the Palliative Approach (PEPA)

Free PEPA mentors breakfast meeting. This talk will focus on the mentoring process in multidisciplinary supervised clinical placement programs such as PEPA. This is designed to be an introduction to clinical placement mentoring for PEPA host sites in Queensland.

While this talk will focus on the PEPA program requirements, it would be a

good introduction to mentoring for any health professional involved in clinical placements. It is hoped that this workshop will be followed up with a more involved look at mentoring in the near future.

7.00 am Tuesday 26th May, Seminar Room 1

Education Centre, Royal Brisbane and Women's Hospital

RSVP, Kathy Laurent (07) 3636 6216, Kathryn_Laurent@health.qld.gov.au

Program of Experience in the Palliative Approach (PEPA)

Free PEPA General Practitioner Education Evening Wednesday 15th July with guest speaker Professor Janet Hardy, Director Mater Palliative Care Service speaking on "What's new in symptom control?". This event will be accredited for RACGP QA & CPD Category 2 points.

Venue: Diana Plaza Hotel, Woolloongabba Times: 6.30 pm to 9.00 pm.

RSVP Kathy Laurent, PEPA Program Manager Qld on (07) 3636 6216 or Kathryn_Laurent@health.qld.gov.au. Note, this event includes a free 2 course dinner.

CANCER COUNCIL QUEENSLAND

Cancer Council Queensland's Oncology Nurses Group and Allied Health Professionals Oncology Group invites all health professionals to a free education forum 'Cancer care for the elderly'. Speakers to include a Clinical Nurse Consultant, General Practitioner and a Nurse Practitioner, Palliative Care/Aged Care

Wed 3rd June, registration and light refreshments from 5.00pm, presentations 5.30-7.30pm with a light supper to follow. CCQ Auditorium, Gregory Terrace, Fortitude Valley

RSVP by Monday 1st June to Judith Whitehead (07) 3258 2267 or ong@cancerqld.org.au

Palliative Care Vacancies

Chief Executive Officer - Palliative Care Queensland (PCQ)

PCQ is the peak representative body for palliative care and end-of-life care in Queensland, with over 200 members, including members of the general public, health professionals and organisations whose core business includes the provision of palliative care or end-of-life care. The Chief Executive Officer will work closely with PCQ State Council to ensure the execution of both the organisation's strategic and operational plans. The CEO will also provide consultation to the President and Management Committee in relation to strategic issues within the palliative care and end-of-life care sector, as well as providing operational support and consultation.

Applications are sought from individuals with demonstrated experience in human resource management, strategic planning and operational management experience. It is also a requirement that applicants have an excellent understanding of the current issues impacting upon the palliative care and end-of-life care sector in Queensland, and an excellent understanding of the issues affecting the health industry in Queensland more broadly. This is also a leadership position that requires excellent communication, negotiation and presentation skills.

For further information about this position, please contact John-Paul Kristensen, Acting Executive Manager PCQ on **(07) 3633 0096** or visit **www.palliativecareqld.org.au**. In the first instance, applicants are requested to forward a letter of application, providing an overview of their professional experience and suitability for the position together with curriculum vitae to PCQ by 12.00 pm on Friday June 5th 2009.

TEAM LEADER/SOCIAL WORKER – PALLIATIVE CARE INFORMATION SERVICE (PCIS)

The Palliative Care Information Service is a free statewide telephone based information and support service available to all Queenslanders affected by life-limiting health conditions. An exiting opportunity exists for team a leader/social worker to join our team. The primary responsibility of this role is to consult with a range of clinical and non-clinical professionals in the palliative and end-of-life care sector, and to be part of a team of telephone counsellors who provide high quality support and information about palliative care.

The position is 4-5 days and an attractive salary will be paid to the right candidate. Preferred applicants will possess a tertiary qualification in Social Work with at least two years experience in the health care industry. For more information about this position, visit **www.seek.com.au** or call Kay Powell, Services General Manager on **(07) 3632 8313**.

COUNSELLOR/INFORMATION OFFICER - PALLIATIVE CARE INFORMATION SERVICE (PCIS)

The Palliative Care Information Service is a free statewide telephone based information and support service available to all Queenslanders affected by life-limiting health conditions. An exiting opportunity exists for a telephone counsellor/information officer to join our team. Preferred applicants will possess a tertiary qualification in counselling/social work with experience in grief and loss counselling, and will be computer literate, motivated and a good communicator.

The position is part-time and an attractive salary will be paid to the right candidate. For more information about this position, visit **www.seek.com.au** or call Kay Powell, Services General Manager on **(07) 3632 8313**.



Together! 2009 Cultural Connections for Quality Care at the End of Life

September 24 – 27 Perth Convention and Exhibition Centre

EXCITING NEWS FOR DELEGATES, SPONSORS AND EXHIBITORS

Planning for Together! 2009 Cultural Connections for Quality Care at the End of Life is moving along quickly. This conference is the primary event in 2009 for all who share an interest in quality care at the end of life. Representatives of all sectors of palliative care will be present in Perth in September.

PROGRAM

The interest in the conference is huge – over 630 abstracts were received, at least half of which were from international delegates. Abstracts are now being reviewed and the program finalised.

All guest speakers have been confirmed. The speaker list is:

- **Professor Rod MacLeod**
Auckland University NZ
- **Professor Sheila Payne**
Lancaster University UK
- **Dr Bernadette Tobin**
Plunkett Centre for Ethics AUS
- **Dr Bee Wee**
Oxford University UK
- **Dr Elizabeth Gwyther**
Hospice Palliative Care Association of South Africa SAF
- **Dr Stephen Connor**
Worldwide Palliative Care Alliance USA
- **Dr Reena George**
Christian Medical College, Vellore IND
- **Dr M R Rajagopal**
Pallium India IND
- **Ms Liese Groot Alberts**
Grief and spirituality expert NZ

SPONSORSHIP AND EXHIBITION

Trade exhibition booths in good positions are still available for sale. Great packages can be put together ensuring the needs of your organisation are met at Together! 2009.

REGISTRATION

A group booking rate is also available – for more information visit the conference website on www.conlog.com.au/palliativecare/groupbookings.

For conference enquiries:

CONFERENCE LOGISTICS

www.conlog.com.au/palliativecare2009

Ph +61 2 6281 6624

For sponsorship or exhibition bookings, contact Gretchen Irvine or Donna Daniell on 02 6232 4433.



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