Welcome to another edition of PalliativeProfileSA.

What an exciting and very busy few months it has been. We have been in the offices of senior bureaucrats and politicians pursuing key advocacy issues, negotiating management agreements for the PEPA program for South Australia, obtaining ministerial support for the Palliative Care Awards 2011, and surveying Private Health insurers to underpin a position paper about the diminishing level of member benefits for palliative care at home. Add to that the modernisation, redesign and upgrade of pallcare.asn.au and a 70km Hospice to Hospice Lap of Adelaide to celebrate National Palliative Care Week, and you will understand things have been a little hectic to say the least.

With the focus of this issue on Palliative Care beyond that of cancer, we include a number of reports showcasing the project work being done integrating palliative care across the wider health environment and look forward to bringing you more in the next issue about the findings of new research that reveals disease progression in COPD as unpredictable with no clear transition to a period that can be identified as ‘end of life’ and hence the difficulty often faced in making an accurate and timely diagnosis of dying in the non-malignant patient population, and the communication challenges this brings. ‘Talking to patients about death and dying – discussing patient concerns’ is an excellent resource in this regard and available from PCCSA.

In Comments Corner this month we talk about the notion of ‘un feu sacre’ – the illuminating and driving passion that energises and inspires a person’s or a group’s life and work and pose the question “is the hospice movement dead - can palliative care survive its transition into the mainstream culture?” You be the judge, we list a number of editorial and research articles for further reading.

We wish Wendy Jansen, winner of the Dianna Rudd Scholarship in 2009 an informative and interesting visit to NZ where she will be looking at the Liverpool Care Pathways Project and other models of care. She leaves on July 24th and embark on a week long whirlwind tour of 4 hospice and palliative care services in the North Island. We look forward to hearing of her insights upon her return.

Mark Butler’s announcement of a further $3million being allocated through Palliative Care Australia to support a palliative care equipment loan scheme was welcome news and we look forward to bringing you more detail about how that will work on the ground.

So sit back and relax with a cup of your favourite. We hope you find this edition of PalliativeProfileSA motivating and thought provoking.

Tracey Watters
Executive Officer
PCCSA

Tracey Watters starting on her Hospice to Hospice Lap!
Palliative Care services have been challenged to ensure that palliative care is available to all people who need it, regardless of their diagnosis. In 2000, the first National Palliative Care Strategy was published emphasizing that “The need for palliative care depends not on any specific diagnosis, but on the person’s needs; in particular, it depends on the complexity and severity of a person’s distress or potential for distress.” It went on to list “some of the more common medical conditions of people needing palliative care” which included “cancer, HIV/AIDS, motor neurone disease, muscular dystrophy, cystic fibrosis, multiple sclerosis, end-stage dementia and end-stage respiratory, cardiac, renal and liver disease.”

The recent update of the National Strategy also highlights unmet needs in certain population and patient groups, including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, people living in rural and remote locations, people who are socially or financially disadvantaged, veterans and their families, people living alone, people in the justice system, children and adolescents, people with mental health issues, people with disabilities and people with life limiting non-malignant conditions.

In South Australia, and indeed Australia, although people have not been excluded from specialist palliative care on the basis of diagnosis or circumstance, the patients seen by our adult services are still overwhelmingly those with a cancer diagnosis. Extending palliative care to reach all these under-represented patient groups is now the subject of significant research. And there is not likely to be just one answer, as each of these groups carries its own particular needs.

In this issue of PalliativeProfileSA there are several important articles reporting on work that is ongoing in Adelaide: two focus on patients with mental health issues who are now in need of palliative care, one including the full range of mental health diagnoses and the other examining the needs of patients with less severe mental illness. Two other papers describe projects designed to support professional and family carers of people with dementia, both at home and in residential aged care facilities, including a focus on rural patients.

Of all our vulnerable populations, these two patient groups must be amongst our most vulnerable. The dementia “epidemic” has been widely acknowledged, but effective ways of providing adequate palliative care to patients and support to carers, particularly at home, remain a challenge. Both these projects describe ways to empower carers through education, and support the personhood of the dementia sufferer -important steps in improving the care environment.

Mental illness, ranging from common, milder forms, to more severe diagnoses has been a challenge to the whole health system for some time. The health system has struggled to meet the needs of patients with mental illness when patients were physically well. How much more difficult must it be to have needs met when a terminal illness supervenes? ABC One’s Background Briefing programme from June 12th 2011, provided heart rending evidence of the difficulties faced by one such patient whose terminal diagnosis was delayed, and suffering neither validated nor relieved, because of her long-standing schizophrenia diagnosis.

At some level, all parts of the health system are competing with each other for funding, each trying to make their case for better outcomes for the group of patients they serve. In the last year or so, the spotlight has finally moved to mental health services. We can only applaud and encourage the improvements that are gradually being gained for mental health patients. But we can also highlight to our mental health planners, the particular plight of those patients now in need of palliative care.

Narratives, patients’ life stories, have an important place in palliative care. Patients, however frail, often make an effort to set down their own record, helping make sense of their lives for themselves and for their loved ones. It seems to me that dementia or a mental health diagnosis both have the potential to turn that coherent narrative into something more like a jig-saw puzzle, with some pieces missing, or with a few pieces inserted from another box. In this situation, carers, both professional and informal, have a vital role to help that person create as whole a picture as possible. And how important it is that all those involved in the care are able to communicate and co-operate to achieve the best possible outcomes.

PalliativeProfileSA is a good place to highlight work in progress in South Australia, and we hope in future editions to focus on more of the work relating to palliative care in other vulnerable patients groups I mentioned at the start. What really are their needs and how can they be met? How can their voice be heard?

We welcome your voice in this ongoing discussion.

Dr Mary Brooksbank
Chairman

1 National Palliative Care Strategy. A National Framework for Palliative Care service Development. Commonwealth of Australia, Commonwealth Department of Health and Aged Care, 2000

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Spirituality in end of life care: don’t just call the chaplain

This aspect of palliative care is often overlooked and there is a growing assumption that spiritual issues will be dealt with by other members of the multidisciplinary team, (most notably the multi-faith chaplain). However, if we believe and agree that hospice and palliative care is holistic care, of which spirituality is an integral part, would we not then see spiritual care as a responsibility of the whole team, while recognising that an individual may hold specific responsibility for ensuring its provision. Read more about a learning tool specifically examining psychosocial issues in pastoral care, counselling and support for health professionals later in PalliativeProfileSA.

Inadequate funding of care for medical patients

In a private study undertaken by Emeritus Professor Ian Maddocks he reveals what he terms as a serious discrepancy being allowed to develop; one which is compromising the opportunity for persons with ‘medical’ as opposed to ‘surgical’ conditions to receive the care they need. He is referring to the increasing closure of small community hospitals and a category of patients, (a high proportion of which have private insurance) consequently being denied the opportunity to have their palliative and terminal care delivered in these small community hospitals and funded under their health insurance policies. His study indicates the important contribution small community hospitals made in helping to relieve the pressure on acute and specialist facilities and further notes home care as often the preferred and most satisfactory place to care for people who are dying. However, we know through a recent survey of health insurers ourselves, private health insurance for palliative care at home is a diminishing concept and whilst Australia has shown the way in many aspects in the programmes for palliative care we are at risk of seeing an erosion of previously excellent services through a failure to recognise that palliative care delivered at home or in a small community hospital is, in most dimensions, superior to what is offered in the large acute hospitals.

Have your voice heard

Comments Corner aims to encourage discussion about the wider issues in palliative care and we welcome your response to any of the material in PalliativeProfileSA.

New Mental Illness pages released on CareSearch

CareSearch aims to update materials and add new information to its website on a regular basis. The website recently added new web pages dealing with Mental Illness.

One in two Australians have experienced an episode of mental illness and one in five currently have symptoms. Depression, trauma and anxiety are the most common. Other conditions like schizophrenia and bipolar are less common. All conditions can lead to complexities in the treatment regime for all health professionals.

The new resources on CareSearch aim to support patients and families and those health professionals caring for them.

Mental illness (Clinical Practice)

Mental illness (For Patients and Families)

The March 2011 nurses (HUB) news has a special edition focus on mental illness and palliative care. This included a discussion starter on mental illness, an overview of resources relating to mental illness available in CareSearch and a spotlight on Katrina Récoché’s work on homelessness.

CareSearch is an online resource funded by the Australian Government Department of Health and Ageing as part of the National Palliative Care Program. CareSearch is free to use and is available at www.caresearch.com.au. For further information on CareSearch contact the project office on (08) 7221 8233 or via email at caresearch@flinders.edu.au
Recently there has been great concern voiced by national mental health organisations and respected clinicians regarding the lack of infrastructure and mental health services currently available to meet the needs of people living with a mental illness. We know that this cohort of people are usually marginalised, socially isolated and tend to avoid health care. The majority of funding and services are focused on ‘recovery’ with mental health services support until an individual is stable when they are handed back to primary health care to manage until the next crisis. But where do these people go for support when they are also faced with a life limiting illness, like cancer or advanced heart, respiratory or liver disease? Who provides palliative care for them and where do they die? The Integrated Mental Health and Palliative Care Task (IMhPaCT) is a consortium of specialist and primary health care services who are interested in providing quality palliative care for people who have a severe persistent mental illness (SPMI) as well as a life limiting illness. A severe persistent mental illness includes such diagnoses as schizophrenia, bipolar disorder and a major depressive disorder. The consortium is being led by the Southern Adelaide Palliative Services (SAPS), a tertiary provider of palliative care to a population of 350,000 people who reside in the southern metropolitan area of Adelaide. Care is delivered across multiple sites, including hospice, private home, residential aged care facility as well as the three general hospitals within the region.

Along with SAPS, the other consortium services include the Royal District Nursing Service SA Inc, Southern Mental Health Services, South East Regional Palliative Service (Mt Gambier/Naracoorte) and the South Coast Palliative Service (Victor Harbor). The project, which began in June 2010, is funded through Round 5 of the Australian Government’s Local Palliative Care Grants Program with a final report to be submitted 30 August 2011. Through their experiences, consortium members have identified that clients with a pre existing severe persistent mental illness are the most challenging to work with including complex psychosocial and physical needs. The current literature clearly states that the physical health of people with mental health problems has long been neglected and it is now at crisis point. Research has found that people with a serious mental illness have a higher mortality and morbidity rate than the general population. (Muir-Cochrane 2006: Foti et al 2005; McGrath and Holewa 2004; Coghlan et al 2001). Vreeland (2007) claims that people with a serious mental illness have 13 to 20 year drop in life expectancy.

The project identified 4 main areas of work that could improve the quality of life until death of these complex clients.

The areas were:

- a) Access to mental health information upon referral to the palliative care service
- b) Developing an improved pathway of care to achieve a coordinated and integrated client focused care plan that includes the caregiver/family
- c) Developing an education program to provide appropriate workforce training for multidisciplinary health care workers from the mental health and palliative care sectors
- d) Sustainability of the project outcomes through the development of key liaison persons in the mental health and palliative care sectors to ensure integration of care and service collaboration after the project.

The project has uncovered more questions than it has found answers for. We acknowledge that twelve months is not enough time to make sweeping changes within either mental health or palliative care services but we have achieved the following outcomes:

- Changes to the palliative care services referral and triage process in order to identify, upon referral, a mental health illness and history. This is being achieved by asking if the person being referred has had a past history and if so, collecting specific information regarding clinicians/services that may already be involved in their care. The question has also been included on the hospital liaison referral form.

- A triage tool is currently being developed that will incorporate feedback from the evaluation of the referral/triage process mentioned above and further conversations that have been held with palliative care clinicians.

- 18 clients were consented into the project and each received an initial joint visit by the Community Palliative Care Nurse and the project Mental Health Nurse Practitioner who conducted a mental health assessment and mental state examination. Discussions were then held between the project Mental Health Nurse Practitioner and Senior Consultant Psychiatrist to plan a coordinated approach to the clients care. 12 case conferences have been held sometimes with the client and their carer but always with the services currently involved with the client. These have proven to be of great value not only to the services involved but to the majority of clients and carers. One carer commented: “I was able to match stories between the client and the different workers. It now makes sense to me what is happening, why, and what my part is within that process.” There will also be further demographic analysis regarding the registered clients and the case conference results.

- Increasing knowledge and understanding of mental health issues for palliative care services and palliative care issues for mental health services. This was achieved through 4 palliative care awareness workshops attended by 65 mental health multidisciplinary clinicians and 4 mental health awareness workshops attended by 37 palliative care nursing and allied health clinicians. There were also joint visits between mental health and palliative care services and the development of a mental health learning package for hospice nurses.
Key mental health and palliative care liaison portfolios are currently being considered and hopefully initiated before the end of the project. These roles will support the ongoing progress of the project outcomes to date and maintain those vital integrated and coordinating processes required to provide better end of life care for people with a SPMI.

The article began with this question and we still have no answer to it. The project team welcomes your feedback and thoughts: “where do people with a SPMI receive their palliative care, if any, and where do they spend their final days?”

For more information on the project process, outcomes and evaluation please contact Janet Taylor.

Janet Taylor, Project Manager and Clinical Practice Consultant
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(08) 8275 1076
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Foti, M. Bartels, S. Van Citters, A. Merriman, M. Fletcher, K; May (2005) Psychiatric Services; End-of-life Treatment Preferences of Persons with Serious Mental Illness; Vol. 56; No. 5; Page 585-591.


A research team from Flinders University discipline of Palliative and Supportive Services, is working in partnership with McCarthy Psychology Services, Bendigo Loddon Primary Care Partnership and six Residential Aged Care Facilities (RACFs) in South Australia and Victoria to build capacity of staff in rural Residential Aged Care Facilities to provide best practice palliative care to people with dementia. The project was Funded by the Australian Government Department of Health and Ageing, Local Palliative Care Grants Program – Round Five.

Rural facilities often miss out on education opportunities available in urban settings. This project set out to redress this imbalance. The project has developed and trialled a unique interactive e-resource specifically designed for rural and remote residential aged care facilities to educate staff, using both small group and individual learning experiences. The learning tool is designed especially to support the translation of knowledge into practice and is aimed at all RACF staff, including care staff, hospitality and management staff.

The appointment, training and support of champions in each facility, with backfill provided by the project so that they had “protected time” for project activities, was an important component of the project. The champions from the SA RACFs have been Sue Becker and Tamara Erskine (Wheatfields Inc, Freeling), Karen Swanson and Barbara Zwarts (Barossa Village, Nuriootpa) and Donna Sheasby (Copperhouse Court, Whyalla).

Development of the educational tool took place in wide consultation with specialists in adult and aged care education, palliative care, dementia care and care provision/management in residential aged care settings. The e-learning disk comprises 21 learning puzzle pieces, preparation tasks and resources. The supported learning process includes input from a character named Dorothy Nightingale, who is a senior nurse who has made the transition to a person centred model of dementia care. Her role is to share her experiences of making this transition or journey of discovery of the pieces of the puzzle with the participants and to encourage them as they work through the learning tasks and put the puzzle together themselves.

In the CD learners are introduced to Bernie McCarthy who acts as a mentor, introducing new content and connecting information and sections of input from videos and interviews. Learners are also introduced to Mary Lennox, who shares her personal reflections on being a resident of a facility and having dementia. Video interviews of palliative care consultants and a family member who has recently lost a loved one after a stay in an aged care home are also included. These mechanisms are designed to give the learner as much opportunity as possible to reflect on the content, understand it and make the shift to best practice palliative care for people living with dementia. It’s effectiveness for one learner was expressed in these words:

“Listening to Mary, the reflection brought out the passion behind it and made it a more personal journal.”

Micro-training is a unique aspect of this learning package, designed as a tool for personalising practice. It contains 26 one minute messages containing core ideas from the learning CD, with a question for brief discussion or reflection. These can be used at handover or other times, to enhance the sustainability of the learning and its translation into practice. Feedback about the Personalising Practice microtraining has been especially enthusiastic.

“There are some really good discussions going on as a result of it…brief discussions, but really good.”

215 staff members have participated in the learning programme to date.

The evaluation phase is currently underway. Data gathered from staff, residents and family members, using a range of evaluation tools, will provide rich information for further developing palliative care for people with dementia. Results from focus groups of staff who have used the learning tool have included comments such as,

“The people who have done the course (e-learning) –their attitudes and perceptions have changed. They participate more in discussions.”

We are grateful for the collaboration with the RACFs in this project and have enjoyed working together to develop new, effective and sustainable ways of improving palliative care for people with dementia.

Meg Hegarty, Sam Davis, Melanie Shanahan, Alison Campbell, Bernie McCarthy
Coordinated Pathways: supporting Carers and Families in a Palliative Approach for Care - Experience from Resthaven Incorporated

Resthaven Inc has managed this co-ordinated pathway project on dementia palliative care for the past 15 months. The purpose of the project was to enhance the quality of life for both the carers and people living with dementia through their illness to the end of life, enabling them to die at home if this is their preference.

Working alongside staff, carers and the person living with dementia, we identified the training needs for staff and information needs of carers. From this information we modified and developed the Australian Palliative Care Community Services Training Package (CHC02) into a 2 day course focusing on dementia care. Approximately 120 staff have attended and the feedback has been very positive. We found staff were thirsty for knowledge on this subject.

The training focuses on the experience of the person living with dementia and the need to acknowledge that their personhood continues until death regardless of the damage to the brain. It gives staff a good understanding of the effects of dementia on the person and how most behaviours are a form of communication. It's up to us to have the imagination to interpret what the person is trying to tell us. A person's experience with dementia is largely up to how we respond to them and support them. The training also takes the staff through the process of dying, the need to work in collaborative teams, the needs of the family and the needs of people with dementia at the end of their lives.

We have developed fact sheets for the family carers on subjects they felt they either didn't have sufficient information on or couldn't access that information. These include activities in the home, advance care planning, anticipatory grief, morphine the myths and the signs of impending death. We have also provided specific one-on-one training when requested around clinical care such as bed baths and manual handling.

We have developed a manual for Coordinators to use as a guide when working with people living with dementia in the community. This helps them in how to get to know a person living with dementia, how to hold family conferences, and information to stretch their thinking about available resources at the end of life stage among other topics.

We have worked with CALD groups and delivered training on Advance Care Planning and we are currently negotiating to have the fact sheets translated into Polish, Serbian and Chinese.

The project will be completed by 30th June with the final report due to DOHA by 31st August 2011. The report will make recommendations on what a dementia palliative care model should look like in the community.

Further information can be obtained by contacting Valerie Sandlant, Project Manager, at Resthaven on 08 8433 0300.

A State-of-the Art Learning Environment in Palliative Care for Rural Health Professionals

An advance in palliative care education examining psychosocial issues in pastoral care, counselling and support.

A palliative care research group led by Associate Professor Mary Oliver and Ms Joy Penman at the University of South Australia have designed and developed a learning tool specifically examining psychosocial issues in pastoral care, counselling and support for health professionals which is proving to be highly successful.

The education resource was developed following a needs assessment to fill a gap identified in resources in the area of pastoral care, counselling and support for rural health professionals. Interviews with eight health professionals working in community palliative care and a comprehensive review of the literature on the topic informed the needs assessment.

Used by many palliative care services and education providers, the multimedia learning resource is a comprehensive resource with a multidisciplinary focus. The product consists of two DVDs and user instructions. The first DVD portrays the story of the young man with a brain cancer and his journey in dealing with the illness. The end of life care provided by family, health professionals and others is portrayed in a moving story, resulting in an empowering experience for the patient and his family. Embedded in this story, using a case-based reasoning (CBR) pedagogy, is an up to date, engaging learning environment which consists of reflective exercises, a library of full text resource materials and a repository of real-life expert cases for the user to interact with in making critical judgments in decision making. These are contained in the second DVD consisting of an introduction, scenarios from the young man’s story, reflective activities, a full-text library and a repository of authentic expert cases.

Art as an expression of coping with end-of-life issues in palliative care is presented in the repository of cases displayed as a gallery. The artwork presented in watercolour was produced by an artist who was diagnosed with a life limiting illness and who used art to illustrate the day-to-day challenges of living with a terminal illness and coping with changing body image. Art is represented as a powerful therapeutic medium to illustrate the emotional upheaval and how this artist came to terms with the daily challenges of a life limiting illness. Each painting is accompanied by a narrative by the artist.

 Users navigate the folders and subfolders and the content seamlessly integrates graphics as well as text files with which the user interacts. The scenarios extracted from the story are embedded with reflective activities and prescribed readings which are accessed from the full-text library provided. The expert cases embedded in the learning environment depicts decision making by experts in several situations.

The user evaluations have shown that the DVD learning environment is ‘versatile, comprehensive and engaging’. It is interactive and can be used as stand-alone and/or in support of other resources in palliative care. The product represents the real world practice in community palliative care and is at the forefront of current thinking in psychosocial care.

Further information and contact details are: mary.oliver@unisa.edu.au joy.penman@unisa.edu.au
My Dad
A poem about my dad; written by Carmen Hofhuis about Joseph Hofhuis.

My dad - The Dutchman, the funny man. His sense of humor, his sense of ‘it will be alright’ and whatever will be will be, has got him through many trials; the war as a child in Holland, the massive transition of leaving his own country and starting a new life in Australia, the work and toil as a builder to develop a life and stability for his family.

My dad – the Dutchman, the funny man, the resilient man. ‘It will be alright’ and whatever happens in life is part of life; the ability to ‘take it all on the chin’ is his strength and health. Whatever he goes through in life, it is not about him. Whatever he does in life it is not about him. What it is all about is how my dad can make it easier for others. This has kept him from tumbling, from being defeated amongst the trials and challenges of life.

My dad – the Dutchman, the funny man, the ultimate missionary. The ultimate missionary. Yes he spent time on the missions in Papua New Guinea, that is where I was born, but that wasn’t his role or job, that is who he is. Wherever he goes, whatever he does, this is the very core of the man who is my dad. I cannot separate the missionary from the man, his sense of giving and doing whatever he can to help someone out, to make it easier for someone else, to make something from nothing and to create a masterpiece, either in building, cake decorating, craftwork or even bringing something home from a visit to the dump which seems unusable but to see what others can’t and create an item which will be ‘just what is needed’ for someone or for me and my sister.

My dad – The Dutchman, the funny man, the man of faith. His faith in God really shines through, his wish when he goes to be with God is summed up in his favourite words of a John Lennon song; ‘Give Peace a Chance’. This is the wish of my dad, that we all will look after each other and have peace in our hearts rather than all the hurt that is in the world. “The opposite of hurt is happiness. The opposite of hatred is forgiveness.” My dad wants to ‘Give Peace a Chance’.

My dad – he can’t do what he used to do anymore, his health is not so good anymore, but still his thoughts aren’t about himself. Yes he regrets not being able to go out and see his birds in the backyard whenever he wants, or to build and be busy in the backyard where he spent so much time, “I don’t have the energy to do what I used to do” he says. He regrets this but his thoughts aren’t about himself. When he was nearly dying and could hardly speak, and his breathing was heavy and the family were called to be by his bedside, I would lean over to him because he wanted to say something – ‘I love you my darling’, my heart melted, I felt like he touched me on the inside. That is my dad, even in his suffering he reaches out to others’, he creates something special which will last beyond himself, the happiness and pleasure he can create by giving of himself, not by design or purpose but that is who he is.

My dad – he can’t do what he used to do anymore, but he is still the person he has always been. The Dutchman, the funny man, the resilient man, the ultimate missionary, the man of faith – my dad.

By Carmen Hofhuis

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* Calls from mobile phones are charged at applicable rates
I commenced my role as Project Officer for The Specialist Mental Health Initiative in Palliative Care in late November 2010; a project funded by a DoHA Palliative Care Round 5 Grant. The project spans the northern region of Adelaide, and partners include; Lyell McEwin and Modbury Level 6 palliative care teams and Level 4 and 2 palliative care teams from the Inner North, Mid North, Lower North and Yorke Peninsula Palliative Care Services.

The main aim of the project is to implement a system for identifying individuals with low to moderate mental health problems at an early stage in their palliative care treatment. This includes the development of additional screening questions to be asked by palliative care staff at the assessment stage, education workshops for palliative care staff to further develop skills in identifying and dealing with low to moderate mental health issues such as anxiety, depression, distress, personality disorder and bipolar disorder. As part of the project we are looking at introducing routine screening for pain and distress using an electronic screening tool called Quicatouch. Quicatouch was developed by Newcastle University and used on Oncology wards to measure patient levels of pain and distress. Quicatouch provides a score upon completion of the screening tool, which is indicative of the type of psychosocial intervention that would be beneficial for the patient. It is important to note that the tool has been validated on 10,000 patients. Results indicated that repeat screening for this group of patients contributed to the reduction of levels of pain and distress by more than half. This is due to the early identification of psychosocial issues and the appropriate intervention to assist in the reduction of distress.

As Project Officer I am responsible for delivery of the project outcomes. A reference group of professionals from a range of backgrounds oversee the work plan and milestones.

Andrea Gregory, an Emotional Wellbeing Counsellor and Psychologist, is employed by the Northern Division of General Practitioners and is part of the project through a developing relationship with the northern area palliative care services. Andrea provides support to palliative care clinical staff in managing patients with low to moderate mental health problems, provides relevant content for the Education workshops and takes the lead for delivery of these workshops.

Lisa Minopoulos is the Project Administrator, responsible for the day to day administrative tasks as well as providing practical support to the team and participating in project tasks.

To get an idea of our starting point, in 2007 the second National Mental Health Survey identified that at any one time approximately 1 in 5 (20%) of the population in Australia suffers with a mental health problem such as depression. A case file audit of 220 patient files identified that less than 1% had documentation noting a drug or alcohol issue and less than 10% as having a mental health issue. In most cases this is because a simple screening process was not undertaken therefore this important information can be missed. The project aims to improve identification of these problems earlier in the course of illness and implement a care plan relevant to this.

In April, Dr Chris Drummond, Clinical Lead Palliative Care and I attended a workshop to present the project to the Commonwealth. Of the 23 Round 5 projects only 7 had a mental health focus whilst the remainder are exploring dementia and aged care.

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Euthanasia – untangling the confusion

This letter was submitted to the Advertiser in April but missed the furor of the debate “Criminal Law Consolidation (Medical Defences – End of Life arrangements) Amendment Bill 2011” and was not published.

Amongst many letters addressing the question of voluntary euthanasia and in particular the Criminal Law Consolidation Amendment Bill currently before Parliament, there persists uncertainty and confusion around the practice of Palliative Care in South Australia. For example Dr Robert Marr from Sydney (The Advertiser, 6.4.11) wrote of the fear of a doctor of being charged with murder “by helping to make a patient’s death more peaceful”.

Sixteen years ago, the Consent to Medical Treatment and Palliative Care Act 1995 removed this fear for doctors in SA who are treating a terminally ill patient and who give medication “with the intention of relieving pain or distress, with the consent of the patient or their representative, and in good faith and without negligence, and in accordance with the proper professional standards of palliative care, even if an incidental effect of the treatment is to hasten the death of the patient”.

While this supports the use of medication to relieve pain and distress, the Act goes on to specifically state that it “does not authorize the administration of medical treatment for the purpose of causing the death of the person to whom the treatment is administered”.

The Consent to Medical Treatment and Palliative Care Act 1995 also sets out ways in which patients can make their wishes known about the types of treatments they would want, or would want to avoid, at the end of life. The South Australian Advance Directives Review completed in 2008 has recommended ways in which this process can be simplified, but as yet there have been no changes to the legislation.

Palliative care has a great deal to offer in improving the quality of life for people living with, and ultimately dying from, a terminal illness. Combined with easily accessible Advance Directives providing peace of mind for patients and families who find themselves in this situation, many anxieties about death and dying should be relieved.

The current Bill must be seen as a bill for Euthanasia and voted on in that light.

Dr Mary Brooksbank
Chair PCCSA

The Palliative Care Outcomes Collaboration (PCOC) continues in SA with 14 services collecting and submitting data. The SA quality improvement network meeting was held on April 8th with 20 people attending from 10 services. Rob Gordon the Deputy Director of the Centre for Health Services Development at University of Wollongong and Chair of the Version 3 working group presented to the group on the progress of the V3 dataset which will be implemented in July 2012.

Services are looking forward to the annual benchmarking meetings to be held across the country in June, with opportunities to work collaboratively towards best practice.

Deb Rawlings
PCOC South SA/NT

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The Ambrose Centre for Religious Liberty is pleased to sponsor a public meeting for interested parties to hear Professor Margaret Somerville AM, FRSC, A.U.A (Pharm.), LL.B. (Hons), D.C.L., LL.D. (Hons. Caus.), on this vital question.

THE BENEFIT OF A PUBLIC MEETING

Some people are confused as to what euthanasia means. It is vital that people interested in this subject understand what is and what is not euthanasia. Professor Somerville clarifies the difference.

Thursday
7th July 2011
6pm
Olympic Hall
288 Franklin Street
ADELAIDE
ALL WELCOME

Hear the facts for yourself, attend the public meeting

Professor Somerville is an internationally acclaimed and respected leading advocate for the case against euthanasia. She holds the Samuel Gale Chair of Law at McGill University in Montreal.

Professor Somerville holds professorships in both the Faculty of Law - where she holds the Samuel Gale Chair - and the Faculty of Medicine and was the founding director of the McGill Centre for Medicine, Ethics and Law.

Professor Somerville has consulted for international organisations such as the Global Programme on AIDS of the World Health Organisation, UNAIDS, the United Nations Human Rights Commission in Geneva, and law reform commissions in Canada and Australia.

When I first asked myself what could I possibly do to help acknowledge and bring attention to the importance of Palliative Care during National Palliative Care Week, running a 70km hospice to hospice lap of Adelaide seemed like a reasonable idea? It would be a run to remember and therefore it was also a great opportunity to launch Care beyond Cure, the promotional brand under which the Palliative Care Council South Australia, Mary Potter Foundation, Daw House Hospice Foundation and Modbury Hospice have united to promote the state wide awareness and fundraising campaign called Time to Remember beginning in October.

I set myself a simple 8 week training regimen which included many laps of the West Lakes rowing regatta course and the odd gallop along the beach and foreshore from Tennyson to Glenelg. It was along that training route that I literally floundered past PCCSA ex Deputy Chair, Megan Hender, who was out for a morning walk with her dog (and partner). Thanks Megan for your encouragement and enthusiasm!

Right at that time I was quite sure I had bitten off more than I could chew, but having spouted forth my plans and fundraising target I knew I then had to ‘front up’. Remember too, that at this time the mornings/days were a pleasant 20 – 25 or so degrees, quite the running weather. It became quite clear one week out from National Palliative Care Week that May officially brings winter in Adelaide and the weather was slowly but surely packing up!

D Day arrived; Sunday 22nd May; day one of National Palliative Care week. The sun was shining as I left Modbury Hospital car park and I was well into the journey before the rain arrived. I made it to Daw House in 3 hours and 35 minutes, and in quite good nick except for two toes. I hadn’t accounted for the downhill impact. Leg 2 from Daw House to PCCSA was a dodgle compared to the half marathon distance of the first leg and the 6 k’s from PCCSA to Mary Potter was downright pleasant. I was getting a little leg weary by Friday with the 4th leg from Mary Potter to TQEH. Finally Saturday loomed and with it the last leg of my circuit - 20kms uphill from TQEH to Modbury Hospital car park. Phew!! I made it, only just though, the lights at the pedestrian crossing on Woodville and Torrens Roads took forever to change and as a consequence I cooled a little. When they finally changed and I stepped out to recommence the slow shuffle (called running), ping! went my hamstring. So it was a slow but steady walk for the last leg but completed none the less.

It was a fabulous experience and one I would repeat in a minute. A foot soldiers tour of the city and one that is usually seen from the driver’s seat of my car!! I must say a very big thank you to Jim (my husband) and Sally (my colleague) for their unstinting support throughout the week long run, and to Janet Taylor, Lawrie Palmer and Leeanne Tripodi, the SAPS and Mary Potter teams for great send offs, and especially my donor supporters, together we raised over $2800.

So here is the challenge for 2012. Make it an Ekiden – that’s a relay run over a marathon (or longer) distance and consists of teams of 6 competitors who wear a traditional Japanese tasuki sash instead of carrying a baton. Will your hospice or palliative care service enter a team and run a leg of the circuit? I will circulate a call to action early next year. You can of course start training anytime.

Tracey Watters
PCCSA

The finish line at last!!!
PCCSA EVENTS

7th July 2011
Professor Margaret Somerville - 6pm
Public Meeting Olympic Hall 283
Franklin St, Adelaide. All Welcome

July/August 2011
Diary note – a presentation of Local Palliative Care Round 5 projects’ Information at www.pallcare.asn.au coming soon.

3-7th October 2011
Professor Eric Cassell, (program to be advised) Author of The Healer’s Art, The Place of the Humanities in Medicine, Changing Values in Medicine, two volumes on doctor patient communication entitled Talking with Patients, Doctoring: The Place of the Humanities in Medicine, and The Nature of Suffering, now in its second edition. A new book, The Nature of Healing will be published in 2011. He was one of the first to write about and clarify the place of the person in clinical medicine.

1st - 31st October 2011
Time to Remember campaign. This is no ordinary appeal! The focus for the entire month of October 2011 is “remembering how special life is”. Let’s not leave it until we are dying to express our love and appreciation of family and friends. Celebrate the memory of your loved ones by getting together around a table to share a meal, friendship, family and memories, while at the same time raising funds for the Hospice or palliative care service of your choice. The concept is simple; be a host and organise a get together with friends and family, workmates or club associates, have some fun and ask your guests to donate for care beyond cure because caring is as important as curing. You’ll be helping your local hospice or palliative care service provide care to people living with a terminal illness. More info visit www.timetoremember.org.au

30th October 2011 Join us at Barristers Block Winery for lunch, and music to remember, from the 60’s, 70’s and 80’s with popular cover band JD and the Crabs. A Time to Remember event. Information will be available soon at www.pallcare.asn.au

CONFERENCES AND PROFESSIONAL MEETINGS

11-13 July 2011
4th Australian Conference On Spirituality And Health - ADELAIDE
The theme of this Conference is Forgiveness, Spirituality and Health; From Brokenness to Wholeness For further information, visit: http://www.spiritualityhealth.org.au/page.asp?parentid=69

14-17 July 2011
9th Asia Pacific Hospice Conference in Penang, Malaysia. The theme of the conference is ‘to share, to learn and advance caring’.

29-30 July 2011 ANZSPM Medical and Surgical Update for medicine specialists and trainees, GP’s and Specialists and Nurse Practitioners with an interest in Palliative Medicine. anzspm@willorganise.com.au; www.anzspm.org.au

30 Aug - 2 Sep 2011
Conference: Australian Palliative Care Conference
The 11th Australian Palliative Care Conference will be held in Cairns from 30 August to 2 September 2011. You can learn much more about the Conference by following the link from the Palliative Care Australia website, or calling the organisers on 02 8204 0770.

23-27 October 2011
9th Asia Oceania Congress of Geriatrics and Gerontology Melbourne Convention and Exhibition Ctr www.ageing2011.com e: info@ageing2011.com

If you’re a great host... here’s a great cause!

HOST • REMEMBER • CELEBRATE • DONATE

This October we’re asking you to become a host of your own ‘Time to Remember’ event. Take time to celebrate and remember the lives of loved ones who are no longer with us while raising vital funds to support and care for people with a terminal illness and their families.

All you have to do is host a lunch, dinner, BBQ or anything you wish with your family and friends and ask them for a donation. Your event can be as formal or informal as you like.

To find out more or to download a Hosting Kit visit our website www.timetoremember.org.au

“I encourage everyone to get together with their friends and loved ones and be a part of Time to Remember.

I’ll be hosting a very personal event and I invite you to do the same – together we can make a difference.”

Jane Reilly - Ambassador

www.TimeToRemember.org.au
Time to Remember is an appeal by Care Beyond Cure on behalf of hospice and palliative care services of South Australia

202 Greenhill Road, Eastwood, SA 5063 Phone: 08 8291 4137

Palliative Care SA