



**WA STATE PALLIATIVE CARE CONFERENCE EDITION
SEPTEMBER 2004**

BIG CHANGES AFOOT?

With a euthanasia bill in the Upper House of our State Parliament and the Labour Government choosing to hold back on its planned end of life legislation that may have enshrined palliative care in an act of parliament, some current services continue to face an uncertain future. Staff and volunteers at the Cancer Council's Cottage Hospice have been informed by management that discussions are being held with the Dept of Health which, in the medium to long term, may see the relocation of Palliative Care beds from the Cottage Hospice into areas of greater need. These changes could eventually result in the closure of the Cottage Hospice. After 17 years the Cottage Hospice finds itself in the wrong place with an over supply of palliative care beds in its immediate area. With St John of God's new Cancer Centre planning the addition of new palliative care beds in Subiaco, Hollywood Hospital spending on a major upgrade of its Palliative Care Unit and Sir Charles Gairdener and Royal Perth Hospitals both developing palliative care services, it is clear that the Cottage Hospice services would be better placed elsewhere. The Board of the Cancer Council has declared its continuing commitment to palliative care and is looking at linking in to recommendations in the Reid review which suggested palliative care units at Armadale, Swan Districts, Joondalup and Rockingham. Meanwhile the outcome of a review of the bed day price paid to non government palliative care providers may influence provision of services in the medium term.



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WA STATE PALLIATIVE CARE CONFERENCE 2004
IMAGINING COMMUNITIES OF CARE - BUILDING BETTER VALUE, CHOICES
AND OUTCOMES
 Thursday 9 and Friday 10 September 2004
 Joondalup Resort



The conference will be officially opened by The Hon Minister for Health on Thursday 9 September 2004 following a Sundowner in the superb environment of the Joondalup Resort. Following the opening,

Geraldine Doogue, ABC Radio and TV presenter, will address a public forum challenging us with an address titled 'Living in Character-Building Times: Strengths, Weaknesses, Opportunities and Threats for the Average Australian'.



Thursday, 9 September 2004

Valuing the Hidden Carer Workshop: 1:00pm – 5:00pm

In recognition of the unique contribution of volunteers and carers to the work of hospice palliative care, an additional program has been developed specifically with this group in mind. This program will be held at Joondalup Resort on Thursday, 9 September. The program features Keynote speaker Noreen Fynn, Executive Director of Carers WA. Registration for this day is itemised on the Registration Form.



Rural Workshop: 1:00pm – 5:00pm

The rural workshop is designed to be an interactive time that will provide rural practitioners with information about issues of special interest to them. Participants will have the opportunity to hear a range of speakers discussing topics such as the Caring Communities projects and an open forum panel discussion will conclude the day.



Public Forum: 7:00pm – 8:30pm

On the evening of Thursday, 9 September a public forum will be held featuring a presentation by Geraldine Doogue, presenter of ABC Local Radio's Sunday Profile and ABC TV's Compass program. This session is open to all interested persons and registration is not required. Donation of a gold coin would be appreciated, however there is no charge for attending this session.

Friday, 10 September 2004



Full Conference Proceedings: 9:00am – 4:30pm

The conference discussions, presentations and workshops will challenge participants to reflect on creative and practical links amongst those who provide care to reach more effectively those who might benefit from a palliative approach. Increasingly we are confronted by terminal illnesses other than cancer and from a palliative approach. Increasingly we are confronted by terminal illnesses other than cancer and looking at new models of care to accommodate a much broader cohort of patients.



A comprehensive conference program includes a targeted medical education program for doctors and streams relating to psycho-social, spiritual needs and models of care. The program will include presentations from Keynote speakers, concurrent sessions and a panel discussion.

Dr Will Cairns, BA, MBBS, FRACGP, FACHPM, Director, Townsville Palliative Care Service, Adjunct Associate Professor, James Cook University Medical School, will present a keynote address on the topic Hitchhiker's Guide to Palliative Care. Will's interests include supporting the provision of palliative care in isolated communities, education for GPs to encourage their participation in domiciliary care, and the support of students and junior staff to help them deal with death and their dying patients. He believes that the principles of palliative care should be applied throughout the health care system





Professor Linda Kristjanson will provide the plenary session on the topic – In Pursuit of Impeccable Attention to Comfort: Facing the Complex and Reaching Beyond. Linda is well known in the West Australian palliative care sector as The Cancer Council of WA Chair of Palliative Care and Associate Dean of Research and Higher Degrees, Faculty of Communications, Health and Sciences, Edith Cowan University. She was chosen as 2002 Australian Telstra Business Woman of the Year.

The West Australian State Palliative Care Conference continues to have an exceptional reputation within Australia and overseas as a quality event; providing learning opportunities, challenging palliative care paradigms and showcasing important developments in the sector.

To obtain a conference brochure, or more information, please contact the Conference Secretariat, Desley Huggins on tel 9242 0305.

MEDICAL OUTREACH SERVICE

Dr Anil Tandon who supervises the Medical Outreach Service out of Sir Charles Gairdener Hospital has completed and submitted his report on what the service has achieved. It is now up to the Dept. of Health to decide on the future of the service the main feature of which is to help maintain patients in their own homes – especially those in rural and remote areas of the state. Many thanks to those who wrote in support of the service.

REVIEW OF BED DAY PRICE

The Dept of Health has contracted Healthcare Management Advisors of Gouger Street, Adelaide, to undertake a review of the bed day price paid by the government for uninsured patients at the Palliative Care Unit (Hollywood), the Cottage Hospice, Murdoch Community Hospice and St John of God, Bunbury. This has been a long running and contentious issue with claims from the non government providers that they have been providing a service at far less than it would cost in a government hospital and consequently placing themselves in financial jeopardy. It is not known when the report will be published.

Watch this space.

CANCER TRIAL

Dr Andrew Dean’s Virtual Cancer Centre set up two years ago is running a nationwide trial to-gether with consortium members Hollywood Hospital, St John of God Healthcare, Silver Chain and Sir Charles Gairdener Hospital. It is hoped the trial will further develop a ‘tool’ that helps patients with cancer take a more active role in their treatment. The secure online patient, MyQuest.com.au, will harness the worldwide web and allow patients to record experiences and responses to treatment and medications. The patient can share this information with selected health professionals who have an interest in his or her treatment. The trial is already underway but more participants are needed. If you are a patient with cancer and want more information about this trial go to www.virtualcancercentre.com and follow the links to the expression of interest form.

MORE FUNDING FOR EQUIPMENT

PCWA has more funds available for equipment grants. \$189,000 has been provided by the Australia Government via the Dept. of Health & Ageing. Contact PCWA if your service is interested in making an application.

STRANGER THAN FICTION!

Men can now take out up to \$2.7 million worth of insurance – on their chest hair. Lloyds of London has produced the policy after being approached by an unnamed celebrity. Reading the small print on the policy is important. It provides men with cover of up to \$2.7 million for permanent loss of chest hair caused by accident. But it does not cover loss through illness or hair that simply falls out. Usual omissions such as loss through war, invasion or revolution are not covered. Neither is hunting on horseback or hang gliding. Fire eaters are also excluded. Claimants must prove loss of 85% of their chest hair, verified by two experts. Last year Lloyds insured another body part for \$27 million – the taste buds of Angela Mount, a wine taster for a supermarket chain.





ASIAN REPORT
Rosalie Shaw former Medical Director,
Palliative Care Unit – Hollywood.

I have now been working in Asia for more than twelve years. What rich and challenging years they have been!

There are now more than 400 organisations or hospitals providing hospice and palliative care in Asia (not including Australia and New Zealand) and the number is increasing every year. However, development is still patchy and the coverage poor in many countries. For instance, despite there being 132 palliative care units in Japan with a total of 2507 beds, it is estimated that only about 4% of terminally ill cancer patients receive palliative care. Hospice home care is very poorly developed in many countries and there are few independent in-patient hospices in Asia – three in Singapore, two in Malaysia (both in Penang), one in Taiwan, and one in Hong Kong.

Palliative care in Australia dates from the early 1980s. However, in Japan, the first palliative care team was set up in Yodogawa Christian Hospital, Osaka, in 1973. Dr Tetsuo Kashiwagi, who has been a major figure in the development of hospice in Japan, first became interested in care of terminally ill patients during the years 1969 - 1972 while a Psychiatry Resident at the Washington University, Missouri. It was here that he was first exposed to the concept of OCDP (Organised Care of the Dying Patient), a term being used by Dr Melvin Krant. When he returned to Japan he introduced OCDP in the hospital where he was working.



THE MEDICAL TEAM AT YODOGAWA CHRISTIAN HOSPITAL IN OSAKA

In 1979 Dr Kashiwagi made plans to visit Dr Cicely Saunders at St Christopher’s Hospice and Dr Derek Doyle at St Columba’s Hospice in Edinburgh. His encounter with Dr Cicely Saunders changed the direction of his medical career. When he told her that he was a psychiatrist and that he wanted to set up hospice in Japan, she said to him, “If I were a patient in pain, I would not want to see a psychiatrist who tried to relieve my anxiety. And I would not want a pastor who prayed with me. The first person I would want to see is a physician who knows how to relieve my pain.” Following this conversation Dr Kashiwagi decided to repeat his residency, this time in internal medicine and oncology.

Many of the leading figures in hospice in Asia are extraordinary human beings. One of these is Dr Shigeaki Hinohara who has been a mentor for many during his long life. Dr Hinohara is now 92 years old but still fit and working harder than most of us. In 2001 he told a reporter for the Daily Yomiuru newspaper in Japan, that he does not necessarily subscribe to the theory that one must follow a regular daily routine to stay healthy. It is not uncommon for him to stay up until 5 am to write, sleep for an hour and then get up, drink a glass of milk and a cup of coffee before going out to meet his appointments for the day. In the past 60 years Dr Hinohara has written 3200 medical papers and over 300 books.

In 1990, when Dr Hinohara visited the Cottage Hospice in Perth, Western Australia, he was so impressed by the building that he invited the architect, Ian Watson, to design the Peace House Hospice, Japan’s first independent hospice. The Peace House is on a beautiful hilltop site facing towards Mt Fuji, in Kanagawa Prefecture, about an hour’s drive south west of Tokyo.



THE PEACE HOUSE HOSPICE

Dr Hinohara heads five foundations, in addition to being the President of St Luke’s International Hospital in Tokyo. In 2001 he started a new movement in Japan. One of his latest books Shin Rojin o Ikiru (Living as an Elderly Citizen) encourages people over 75 to be active,

creative and enjoy life. It was he who started the Asia Pacific Hospice Palliative Care Network (APHN), an organisation set up to support and link hospice workers in Asia and since 1999 I have been Executive Director of APHN.

I am often asked about language. How do I manage when I only speak English? How do I communicate with patients and their families? In Singapore this has not been a great problem. Everyone in Singapore has trouble communicating. There is such a mix of races with different languages and dialects that it is difficult to make oneself understood. It is not uncommon to find no one on the ward of a major hospital can speak the dialect of an elderly patient. We all learn to get by with gestures and a few simple words of Mandarin or Malay.

The cultural taboo about telling bad news is perhaps more of a problem than language for Westerners who come to work in Asia. We expect to be able to answer patients' questions directly. We are used to talking openly to the patient about the diagnosis and the prognosis. However, throughout the region, in Japan, Taiwan, Hong Kong, Singapore, Malaysia, doctors often talk first to family members who then ask the doctor not to tell the patient what is happening. They believe that the patient will lose hope and will die sooner if told that the disease is life-threatening. Hospice home care nurses are sometimes asked not to park the hospice car in front of the house lest the neighbours or the patient see the logo and can identify the type of service that is being provided. This conspiracy of silence comes at a cost. Patients' questions are evaded. Unfinished business may not be done. Expensive alternative treatments are sought. Most patients with advanced disease are given herbs or traditional Chinese medicines. However, it is of no avail to tell the family that the patient has the right to know. In many cases the patients themselves have abdicated responsibility for decision-making and when asked if there is anything that they would like to ask will say, "Just talk to my son".

Communication is more subtle than in the west. Voices are not raised. The words are polite even when there is anger. The raising of an eyebrow or the slight shrug of the shoulder may be the only indication that all is not well. Empathy is not shown by words or by touch but by silence and stillness. Palliative care espouses the ethical principle of patient autonomy, and the importance of verbal expression of emotion and of bereavement support. However, in cultures where death is not discussed before it happens, and where elaborate rituals proscribe behaviour in the days following a death, we have to ask ourselves whether what we teach in our palliative care courses is appropriate. I have been challenged by the need to respect different ways of responding to the process of dying. However, I have also learned that in every culture the human heart responds to kindness and concern. If I unintentionally infringe some cultural taboo, I will be forgiven if my focus is on the needs of the patient, and my body language and the tone of my voice conveys a message of compassion.



MRS ERNI KOLOPAKING FROM SURABAYA, INDONESIA AND ROSALIE SHAW

WHAT'S ALL THIS?

"Det var sa det. Nu kan vi laene os tilbage og taenke pa Danmark, antager jeg"

(First reader with the answer by e mail to pcwain@palliativecarewa.asn.au gets a prize..... Clue: Think, Wedding!)





CHINESE PROVERBS.....Virginity like bubble, on prick, all gone.
War does not determine who is right, war determine who is left.

WEST AUSTRALIAN WINNER!



ASHLEY VALMADRE, PROF. LINDA KRIST-JANSON AND PROF. DAVID CURROW

Winning the design award for Palliative Care Australia's national competition and being flown to Canberra for its launch was a enriching and humbling experience.

The opportunity to be at the launch and hear and share in the stories from people who were right there facing the real issues of caring for a person facing death gave me a privileged insight into the relevance of my design to the people it would personally touch.

It was a great honour to be recognised for my design skills on a national scale, having competed against students across Australia. I can say that the award has really boosted my confidence in myself and my graphic design skills . I now look forward to the next challenge in my career, and certainly winning the Palliative Care Australia design award has been a tremendous encouragement toward greater success.

Being presented my award by the Honourable Tony Abbot, Minister for Health, was an amazing honour and although somewhat overwhelming and perhaps even a little bit scary, the media cameras and newspaper interviews were very exciting and a great learning curve, testing my ability to express my views eloquently and succinctly while remaining composed, when in actual fact my knees were sometimes knocking.

I know the experience will prove to be invaluable as I work towards launching my career in graphic design over the next few years. Being invited to Canberra was the greatest experience as it allowed me to meet and interact with people who have been affected by the work of Palliative Care or who are carers themselves. Talk-

ing with them gave me a greater insight into their experiences and the role of a carer. Through this I was reminded of the effects of design and the way that thoughtfully conceived design can change people's perceptions and give them comfort. It was an amazing experience which I will cherish and I thank PCA for their acknowledgement and for allowing me to be a part of such an honourable organisation at a great launch event.

ASHLEY VALMADRE, PERTH

HOSPICE SALE FUNDS NEW RETREAT

The sale of the original Albany Hospice on Princess Royal Drive has helped fund a new retreat to help patients with cancer or other chronic illnesses. Called The New Horizons Complementary Centre and Melaleuca Retreat it will offer patients access to aromatherapy, reiki and Healing Touch therapies. David Oliver from the Brownes Complementary Centre at Sir Charles Gairdener Hospital opened the new retreat to-gether with Coral Banks from Albany, the Treasurer of the Hospice Board. Palliative care services in the Albany region have also benefited from a \$5000 grant to further develop training of volunteers.



LESLEY FORRESTER PALLIATIVE CARE AND PAM JARMAN GRIEF SUPPORT

SOCIAL IMPACT OF CARING

The launch of Palliative Care Week on 24 May 2004 by Sue Ellery, Parliamentary Secretary assisting the Minister for Health, was also the occasion for a presentation by Dr Samar Aoun of ECU on the Palliative Care Australia report on The Social Impact of Caring for Terminally Ill People in Australia. Titled, "...the hardest thing we have ever done..." the 72 page report zeros in on what many who work in palliative care have always suspected but never had the resources to prove.



GAIL ROGERS - Speech Pathologist
PRU JAMES - Silver Chain
DR SAMAR AOUN - ECU

Samar Aoun highlighted the report's eleven recommendations which have been presented to the Federal Minister for Health Tony Abbott. In context of both the report and the theme for year's palliative care week (Caring for a person with a terminal illness), PCWA formally linked-up with Carers WA, a small non government organisation with similar objectives to palliative care providers. Carers WA together with its national and state counterparts is well funded by Commonwealth and State Governments. Palliative Care Australia launched the National Inquiry into the Social Impact of Caring in mid 2003 to gather policy, opinion, experience and research data related to the social impact of unpaid caring for the terminally ill. Professor Linda Kristjanson and Dr Samar Aoun of ECU were contracted to undertake the Inquiry with funding from the Australian Government's Department of Health & Ageing. Reinforcing the data from the report Lorraine Kember, whose husband died of mesothelioma, also spoke of her experiences at the Palliative Care Week launch. Lorraine's first hand experiences have been captured in graphic detail in her book 'Lean on Me'

which is available from Lorraine by calling 08 9377 0355 or email: lorakeet@iinet.net.au. Price per copy \$24.50 plus \$4 post and handling. Total \$28.50. Lorraine's book comes highly recommended by numerous palliative care professionals who see it as a helpful teaching aide as well as helpful to carers



JANE REDOLATTI - Dept. of Health
KARLA HAMPSHIRE - Metro South Carer's Respite
JUDY



PRU JAMES, KIM SKETT, KAREN NEALE
VAL DUFF, KERRY COUSINS
ROSELEEN GREENE

Silver Chain Hospice Staff

'PALLIATIVE CARING AT HOME' BOOKS

If you would like to obtain copies of this superb little book they are available for \$3.00 per copy, plus p&p from the PCWA office.





USA COURT UPHOLDS EUTHANASIA

The United States Court of Appeals has upheld the state of Oregon's euthanasia laws. The Court ruled that the Federal Attorney General John Ashcroft had overstepped his authority in trying to punish doctors who prescribed suicide drugs under Oregon state law. Oregon passed their law in two separate referendums. Even former opponents of the legislation say the widespread abuses predicted have not occurred. Oregon's law allows adults with terminal diseases who are likely to die within 6 months to obtain lethal doses of drugs from their doctors. The Oregon Hospice Association estimates that one out of a hundred individuals who begin the process of asking about assisted suicide will carry it out. Since 1997, 171 patients with terminal illness have taken their own lives according to the Oregon Dept of Health. Ann Jackson of the Oregon Hospice Association said surveys of patients were changing the association's practices. In 1994 the Association opposed the Death with Dignity law. To-day the Association's members work with programmes like Compassion in Dying, a group that is involved in 75% of Oregon's assisted suicides. Through one of the surveys Ms Jackson said that they learnt that half the people who rejected hospice care did so because "they thought that hospice was condescending or arrogant". Dr Kenneth Stevens, who heads up the Dept of Radiation Oncology at the Oregon Health & Science University in Portland says it violates the fundamental tenet of medicine. Dr Stevens, a member of Physicians for Compassionate Care, says " I went into medicine to help people. I didn't go into medicine to give people a prescription for them to die"

Mail has recently been arriving to PCWA addressed to our previous administrator Ms Heather GILMORE as Ms Heather KILMORE - not really appropriate for Palliative Care!



PCWA (INC) EUTHANASIA STATEMENT

PALLIATIVE CARE IS SPECIALISED HEALTH CARE OF DYING PEOPLE, AIMING TO MAXIMISE QUALITY OF LIFE AND ASSIST FAMILIES AND CARERS DURING AND AFTER DEATH. PALLIATIVE CARE DOES NOT SET OUT TO EXTEND A PATIENT'S LIFE BY ARTIFICIAL OR INTRUSIVE MEANS.

EUTHANASIA IS ABOUT DELIBERATELY ENDING A PATIENT'S LIFE

PALLIATIVE CARE WA DOES NOT SUPPORT ANY ACTION WHICH HAS THE DELIBERATE INTENTION OF TERMINATING A PATIENT'S LIFE.

- Euthanasia is a confusing term and means different things to different people. There is a wide divergence of views about what euthanasia is.

- It is important that there is informed public discussion about euthanasia and palliative care. Palliative Care WA will continue its role in educating the community about what palliative care is and what it provides patients and their carers.

- Palliative Care WA believes that state-wide adequate funding of community based programs and specialist inpatient care facilities, both to the highest national standards, should occur before embarking on further debate over euthanasia.

- Palliative Care WA supports the need for legal status for advanced directives, living wills or enduring power of attorney in a medical setting. It is also important that formal processes covering access to and use of advanced directives accompanies any legislation. In this era of informed decision making it is important that a patient's wishes are known.

- Palliative Care WA also supports the need for reform of criminal statutes which presently may be interpreted to limit the rights of patients to decline treatment and the role of doctors to withdraw or

refrain from providing futile life-prolonging treatments.

- Palliative Care providers in Western Australia will continue to offer a safe and comforting environment for their patients and their carers.

NEW WHO GUIDELINES

The World Health Organisation has just released new guidelines to promote the proper use of alternative medicines. Since traditional, complementary and alternative (some say unproven) medicines remain largely unregulated, consumers worldwide need to be informed and given the tools to access appropriate, safe and hopefully, effective treatment. As the use of traditional or alternative medicines increases, so do reports of adverse reactions. Dr Lee Jong-Wook the recently appointed Director General of WHO says "WHO supports traditional and alternative medicines when these have demonstrated benefits for the patient and minimal risks". Amongst the recommendations for governments are that consumers should have easily accessed channels to report adverse reactions and that practitioners are appropriately qualified and registered. And for consumers, the advice is that they should ensure that the therapy is suitable for their disease/condition and are the herbal medicinal or alternative preparations of assured quality and what are the contraindications and precautions of the products or materials. This all sounds like good advice but trying to get the information suggested in Australia would not be easy at present, especially for a patient with a limited prognosis. The NH & MRC has recently funded research projects into alternative treatments and hopefully some of these will provide more specific and accurate information not available at present.

CANCER PATIENTS MISSING OUT ON PALLIATIVE CARE

**ABC RADIO REPORT THURSDAY 24
JUNE 2004 – 18.45**

MARK COLVIN: Almost half of all cancer patients in Australia are missing out on palliative care because their doctors are not referring them on for extra support.

Those are the findings of a new study which surveyed a thousand doctors across the country over the past 12 months. It was done by the New South Wales Cancer Council, as Rebecca Barrett reports.

REBECCA BARRETT: Merylyn Stone didn't want to know about palliative care when she was first diagnosed with breast cancer in 1990.

When it came back eleven years later, on her 50th birthday, she still thought it was just for the dying.

MERRILYN STONE: I believe that I was cured, having gone so long and I got to speak to palliative care in December when I was advised that I needed to take more morphine and I was terrified of morphine and I thought people telling me that I need palliative care were gently pushing me into my coffin.

REBECCA BARRETT: It's a common misconception according to the New South Wales Cancer Council.

Its study of a thousand GP's and oncologists around the country found almost half of their cancer patients who needed palliative care were not offered it.

Study author Associate Professor Afaf Girgis.

AFAF GIRGIS: It's very much seen by the community, by cancer patients and by doctors largely as care at when people are at death's door virtually and I think, you know, palliative care could really benefit from a total revamp in the community's perceptions about what it has to offer.

REBECCA BARRETT: Dr Kendra Sundquist, the manager of supportive care at the Cancer Council agrees that palliative care has an image problem.

KENDRA SUNDQUIST: The big issue is that palliative care has a bad image. When people think of palliative care they think of death and so there is a reluctance to talk about palliative care, but palliative care is holistic care for people with advanced cancer and people with advanced cancer can live for many many years.

REBECCA BARRETT: The study found that when doctors did refer cancer patients to palliative care it was mostly for pain control and not for psycho-

logical or emotional support or financial and legal advice

Dr Sundquist says many doctors are so keen to cure their patients, they're unaware that what they really need is palliative care.

KENDRA SUNDEQUEST: Look, oncologists are fantastic; they do an absolutely wonderful job and of course their aim is to cure patients, I mean that's their job. So sometimes this may get in the way. They are just so focussed on curing the patient that they don't think well, they might sort of not, they might miss out on the cues that the patient is giving them.

They need more than just treatment. They actually need some of their emotional and practical support needs met.

REBECCA BARRETT: Merylyn Stone is reluctant to criticise her doctor but knew she needed extra support.

MERRILYN STONE: I did feel like I was falling through the cracks at one stage, but at the same I didn't feel that it was the doctor's perception. I . I think it was that my oncologist was so busy, so so busy that he was dealing with the medical side of whatever and someone that he needed to do and it was up to me to raise the issues

MARK COLVIN: Merylyn Stone, cancer patient talking to Rebecca Barrett.

DEFINITIONS

Confusion - The confusion of one man multiplied by the number present.

ETC - A sign to make others believe that you know more than you actually do.

Experience - The name men give to their mistakes.

Diplomat - A person who tells you to go to hell in such a way that you actually look forward to the trip.

Politician - One who shakes your hand before elections and your confidence after.



WHO RECEIVES PALLIATIVE CARE IN WESTERN AUSTRALIA?

Researchers at the University of Western Australia have just completed a National Health and Medical Research Council funded study that indicates some startling gaps in specialist palliative care provision.

The first challenge of the study was to determine who should receive palliative care. Focus groups of interested people, including palliative care service providers, agreed that terminally ill people with diseases other than cancer should be included in a service constituency. Three definitions of constituency were determined with the minimal definition comprising death from 10 causes: cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neurone disease/amyotrophic lateral sclerosis, Parkinson's disease, Huntington's disease, Alzheimer's disease and HIV/AIDS. The study then analysed data from public and private hospitals, cancer registration, mortality records and the Silver Chain Nursing Association records for the period July 2001 to December 2002.

Results indicate that between 57.3–74.7% of people did not receive specialist palliative care services (SPCS) in the 12 months before death, depending how palliative care constituency was defined. People who died from a neoplasm (cancer) were significantly more likely to receive SPCS in the 12 months before death than were people who died from exclusively non-neoplasm related diseases. Just over 30% of people with cancer do not receive SPCS whereas nearly 92% of those suffering only from a non cancer condition do not receive SPCS. In addition people who died from exclusively non-neoplasm related diseases had shorter stays in hospital-based SPCS but longer hospital-based admissions compared with people who died from neoplasms

Service coverage in the year preceding death, comparing neoplasm-related and non-neoplasm related deaths (calculated using the minimal estimate n = 13,453), July 2000 to December 2002

	Home-based SPCS only		Hospital SPCS only		Both home-based & hospital SPCS		No SPCS		Total
	n	(per annum) %	n	(per annum) %	n	(per annum) %	n	(per annum) %	n
Neoplasm only	1,768 (707)	23.9	1,385 (554)	18.7	1,859 (744)	25.1	2,387 (955)	32.3	7,399 (2,960)
Non-neoplasm only	169 (68)	3.1	215 (86)	3.9	61 (24)	1.1	5,001 (2000)	91.8	5,446 (2,178)
Both	123 (49)	20.2	80 (32)	13.2	90 (36)	14.8	315 (126)	51.8	608 (243)

SPCS: Specialist palliative care services.

While this study shows who is missing out on palliative care it does not tell us why this may be the case. The researchers will now address issues of met and unmet need in palliative care in their next study commencing this year.

PROJECT TITLE: Palliative Care Constituency, Utilisation and Impact on Health Care: A Western Australian Based Epidemiological and Sociological Study.

INVESTIGATORS: Dr Beverley McNamara, Dr Lorna Rosenwax, Professor D'Arcy Holman, Ms Ellen Nightingale.

For further details contact:

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**WA CENTRE FOR CANCER AND PALLIATIVE CARE,
SCHOOL OF NURSING AND PUBLIC HEALTH, EDITH COWAN UNIVERSITY**

NHMRC GRANTS 2004

SUCCESS FOR PALLIATIVE CARE RESEARCHERS

Professor Linda Kristjanson and Dr Lynn Oldham were among the successful applicants for the last round of the National Health and Medical Research Council (NHMRC) Palliative Care grants. Linda and Lynn and teams received funding for three studies. The first project aims to improve cancer patients' and their family carers' knowledge and attitudes toward pain management. This project will be conducted in Perth (SCGH) and Melbourne (St Vincent's Hospital) over the next two years with Professor Nigel Spry and Professor Sanchia Aranda and Dr Peter Hudson as co-investigators.

The second project seeks to explore the feasibility of palliative approaches as a framework for developing a pain education program for care assistants in residential aged care hostels. Co-investigators for this project include Dr Chris Toye (ECU), Associate Professor Nancy Rees (Curtin University), Isabelle Ellis (Combined University Centre for Rural Health), Helen Walker (WA Cancer Council PC Education Centre) and Helen Flux (Carramar and Mertome Hostels).

The third project aims to explore ways to preserve the dignity of the frail elderly. Linda and Chris head a team of international researchers including Professor Harvey Chochinov and Professor Tom Hassard (University of Manitoba) and Professor Oswald Almeida (University of WA). The approach will document aspects of the seniors' life that they regard as meaningful, want remembered, or of which they are proud. Among the terminally ill, the approach has had positive outcomes. Benefits for elders may include that the approach forms a foundation for holistic care.

As well, Lynn has been awarded the NHMRC Post Doctoral Fellowship for Palliative Care Research. It is awarded for two years and is worth approximately \$130,000. The support of a NHMRC fellowship ensures that Lynn has protected research time to build her research expertise. Lynn says that this prestigious award has come at an important phase of her research career and is invaluable.



DR. LYNN OLDHAM

MEMBERSHIP RENEWALS 2004-2005

Have you remembered to pay your renewal for PCWA Membership? If you are as forgetful as I am then be quick before you are deleted from our records!





ST LUKE'S DAY SERVICE 2004

St Luke's Day Service 2004 is a special service of thanksgiving and remembrance, organised by Palliative Care WA. The service is provided for the family and friends of people who have died within the last twelve months whilst in palliative care. We offer this service each year believing it to be a special opportunity for the bereaved and for staff, to come together to remember those who have died.



The service will be held at:

St Mary's Cathedral, Victoria Square, Perth on Thursday 14 October 2004 at 7.45pm.

The climax of the service is the lighting of hundreds of candles in a Memorial Action of Light. Through this we are enabled to focus upon memories of the past and our hopes for the future.

Following the service there is a supper at Mercedes College, adjacent to the Cathedral. It is a chance to meet with staff and friends in the fellowship of palliative care

NEW PALLIATIVE CARE APPOINTMENT
Sue McKechnie who for 4 1/2 years supervised the Dept. of Health's palliative care programme has left. Her replacement is Mr Clory Carrello.



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