

Palliative Care

PALLIATIVE CARE is specialised health care for dying people, which aims to maximise quality of life and assist families during and after death.



Published by Palliative Care Australia, a subsidiary of the Palliative Care Society of Australia, a not-for-profit organisation. The Palliative Care Society of Australia is a registered charity.

NATIONAL PALLIATIVE CARE WEEK



CONFERENCE EDITION

Palliative Care WA (Inc) 46 Ventnor Ave WEST PERTH WA 6005

CONTACTS	
NATIONAL	Palliative Care Australia 02 6232 4433
ACT	ACT Hospice Palliative Care Society Inc. 02 6723 9606
NSW	Palliative Care Association of NSW 02 9334 1891
NT	Northern Territory Hospice and Palliative Care Association 08 8922 7004
QLD	Palliative Care Queensland Inc. 07 3368 3704
SA	Palliative Care Council of South Australia 08 8291 4137
TAS	Tasmanian Association for Hospice and Palliative Care Inc. 03 6223 5692
	Palliative Care Victoria 03 9594 4444

Volume 2 Issue 1
May 2003

CHANGE THE LAWS

PCWA has been campaigning for end-of-life legislation to be introduced to State Parliament. PCWA's objectives are to improve the medical and legal environments which relate to care of the terminally ill so that health professionals and carers don't face the prospect of mandatory sentences of 15 years for something they may or may not do in the best interests of a patient. This requires amendment's to WA's criminal code. In addition PCWA has called for full legal status for Advanced Health Directives or Living Wills in order to bring us into line with other states in Australia. A computerized registry has also been recommended which would record all Advanced Health Directives and which could be accessed on a confidential basis by a health professional when required. This would benefit the whole health system. The Government has welcomed the idea of end-of-life legislation but given it a low priority on its Parliamentary schedule. It is unlikely to be introduced in the life of this parliament unless the priorities are amended. Within this vacuum is mounting pressure for a debate on euthanasia in the Upper House, following the introduction of a new euthanasia bill by Robin Chapple, Greens MLC.

It is PCWA's view that this is putting the cart before the horse. A debate on euthanasia, like abortion, will cause deep divisions and not help the passing of less controversial end-of-life legislation in the longer term. In the following article David Thorne, Medical Director of Murdoch Community Hospice and on the PCWA Executive Committee provides his perspective on clinical aspects that affect those patients who are unable to make their wishes known:

The medical care of the dying has changed dramatically in the past century. Most patients now have choice! Whereas a century or more ago, there was little or no choice in treatment options for most life-threatening conditions, medical science has now clarified the pathophysiology of most diseases to the extent that:



Dr David Thorne
of Murdoch Community
Hospice

Continued on page 2



St Lukes Day Service

16th October 2003

7:45pm

St Marys Cathedral, Victoria
Square, PERTH

ORDER TODAY

A 42 PAGE BOOKLET TO

HELP FAMILIES

AND CARERS

PALLIATIVE CARING

AT HOME

Available from PCWA

\$3.00 PER COPY

Special points of
interest:

A community Af-
fair *page 4*

Research *page 5*

Palliative Care
for Children *page 8*

Founding Profes-
sor

page 10

NATIONAL PALLIATIVE CARE WEEK 25th-31st MAY



(Continued from page 1)

- the course of a disease without any intervention may be reasonably predicted, and
- the altered course of disease with one or more treatment options is predictable and often quantifiable. (For example it is possible to say that for all patients with colo-rectal cancer the statistical average 5 year survival is 45%.)
What choices can the average patient expect?
- To treat or not to treat
(the consequences of this choice vary depending on the severity of the illness. Not treating may have a relatively inconsequential, whereas not treating a breast lump may be disastrous.)
- If electing to have treatment – what sort of treatment? Typically, surgery, medication or complementary therapies may be considered. (For the diagnosis of cancer, options generally include surgery, cytotoxic chemotherapy, radiation therapy, palliative care or some combination of these therapies.)
- Site of care choices may include homecare (including aged care or supported care settings), hospital care or hospice.

In the last decade particularly, patient choices (especially on treatment options) have tended to be more informed, with a significant number of patients and carers accessing the internet for relevant (and hopefully accurate) information.

Public opinion concerning the proposed legalisation of euthanasia seems to be very much influenced by an over-riding desire for the patient to stay in control of the situation. Many do not realize that with appropriate legislation (already passed in most other Australian jurisdictions) the right of patients to refuse life-prolonging treatment can be undisputedly established. Current palliative care practice (and, indeed, the practice of most other areas of medicine) fully support the right of an adult patient, in a sound state of mind, to refuse treatment even if that refusal will hasten death. Yet, this remains a 'grey' area of Western Australian law, and needs urgent attention.

But what of patients who are not able to exercise choices for themselves at the time of an illness? Usually this is because the patient is confused or unconscious. Less frequently they may have lost all capacity to communicate.

Confusion may be of gradual, insidious onset (eg Alzheimer's Disease) or be the result of the present life-threatening illness, exacerbation of a pre-existing medical illness, adverse effects of treatment, or a combination of these factors.



Whilst we can all readily identify with the situation of a person who is brain-injured from a traumatic accident, and who persists in a vegetative state with essential life processes supported by medical technology, in reality this situation is exceedingly rare. We are far more likely to acquire a progressive life-threatening condition (commonly cardiac disease, stroke or cancer) in which the majority will survive the initial presentation sufficiently long for a likely range of outcomes to be identified and treatment options exist. Put simply, if a heart attack doesn't kill you immediately, a spectrum of outcomes from no discernible ill effect to becoming a "cardiac cripple" are possible. A variety of surgical, medical and lifestyle options present themselves which may influence

(Continued on page 3)



(Continued from page 2)

the long-term outcome.

In a patient who cannot participate in decision-making and who has not provided an Advanced Health Directive or similar authenticated guiding statements, the critical care decisions may be made by the health care professional unilaterally, but supposedly in the best interests of the patient. More frequently these days, the health care team will consult with legal next of kin or other family members. This can be less than satisfactory if there has been no prior discussion with the patient, where the relationship between the patient and their relative has been strained, or where the relative may stand to gain financially from the early demise of the patient!



Advanced Health Directives (AHDs) are variously called anticipatory directives, enduring power of medical attorney or living wills. In jurisdictions where such instruments have been introduced, a patient may generally complete the document when in good health, far in anticipation of any illness, or they might be influenced to attend to this directive at or soon after the time of diagnosis of a serious illness. The AHD is intended to give guidance to the health care professionals on the patient's preferred wishes in treatment choices in the future. In some jurisdictions its' directions are legally binding on health professionals. The AHD may be complemented by the provision for a person to nominate another individual as a proxy who may make decisions on their behalf. In each case, these instruments only apply when the patient is deemed not competent to make decisions for his or herself.

Western Australia currently retains a criminal code that places health professionals and carers potentially at risk for providing good pain relief to a patient, or for failing to provide treatment when it is clearly futile, not in the patient's interests and not desired by them.

The introduction of AHDs and revision of parts of the criminal code to remove responsibility from the doctor who in good faith acquiesces to a patient request not to treat are urgently required reforms. Palliative Care WA believes these matters are so integral to the contemporary desire of patients to have autonomy in decision-making about their health and death that they deserve priority attention by the Government.

“Pop-up” Palliation

This is a national NHMRC study, led by Associate Professor Kate White of Edith Cowan University, in collaboration with the University of Western Sydney and Queensland University of Technology. The study involves rural/remote communities in Western Australia, New South Wales and Queensland.

The study aims to improve the care for palliative care patients and their families in rural/remote communities. A model for providing palliative care services, tailored to local needs and involving local communities, has been developed and will shortly be implemented and evaluated in a number of rural/remote areas in Western Australia, New south Wales and Queensland.

The project officer is David Wall on 08 9273 8580.



A COMMUNITY AFFAIR



*Dr Mary McNulty with her community team.
Dr Mary McNulty, Sister Marguerite Connolly (Chaplin),
Dr Ernie Roza, Lyn Luck RN, Donna Hill RN.*

Mary McNulty is a general practitioner at Woodlands Family Practice, and yet she is not your typical doctor. In addition to this, Mary works as part of a multidisciplinary palliative care team for the not for profit health care organisation Silver Chain.

Mary, who has worked for Silver Chain for more than 15 years, says her initial motivation to join the charitable organisation was the recognition that a noticeable unmet need existed for the care of dying people.

“I felt that taking up such a position would be both hugely rewarding and professionally challenging,” she says, “mainly because there’s the great potential to make a difference to the final chapter in a person’s life.

Silver Chain’s Hospice Care Service, started in association with the Cancer Foundation in 1982, provides a specialised in-home palliative care service which operates 24 hours a day. It aims to support people and their families to remain living at home whilst facing a life limiting disease, thereby helping to optimise their quality of life. GP’s with expertise in palliative care are available around the clock to give expert advice to patients and families.

The service relies on the teamwork of individuals from different disciplines, which in addition to doctors, includes nurses, volunteers, chaplains and counsellors. It has been operating for more than 20 years and now cares for over 2000 people every year.

Mary says this teamwork is vital for good patient care. “No one can provide palliative care alone and being part of a multi-disciplinary team also allows for a great deal of personal support, which is so important when working in a stressful and emotional job.”

Despite the stresses involved, Mary says people with a terminal disease are receiving better care than ever before. “There has been a huge increase in education of health care providers, treatment options and services over the past ten years, which is why palliative care has improved enormously, she says.”

But what drives Mary to keep going in this often sad area of medicine? “I think what I find most rewarding is enabling people to fulfill their wish to be at home for all or part of their terminal illness,” she says. “Being a GP means that I work every day in the local community and am able to visit and treat people in their own home.

“I feel privileged to be part of their final life journey and am inspired by the love and care shown by carers, families, neighbours and friends, not to mention the professionalism and dedication of my nursing and other colleagues.”



BIG RESEARCH DRIVE

Since Linda Kristjanson was appointed to the new Cancer Foundation Chair of Palliative Care at Edith Cowan University there has been a surge in research activity both at a national and local level. A real feather in the cap for ECU has been winning the contract from Canberra to undertake the Australian Aged Care Project or APAC. In the past it has always been eastern states universities who have undertaken this type of work but this time Professor Linda Kristjanson's team won the contract against strong opposition. The APAC project is the biggest and most pressured, amongst many others, with a final delivery date for its report and recommendations of December 31st 2003. There is little doubt that palliative care is going to break its historical boundaries by providing structured services for people with longer term diseases such as muscular dystrophy, multiple sclerosis and motor neurone disease – its only a matter of when. Meanwhile, it is research that will provide the concrete base from which new services such as these might be developed. As always the necessary resources and structuring are another vital ingredient.



Assessing Supportive Care Delivery

A national study into the supportive care needs of individuals living with neurodegenerative disorders is being led by Professor Linda Kristjanson and the ECU Cancer Palliative Care Family Health research team. This study is being conducted in three states across Australia to assess the extent to which existing models of supportive care service delivery meet the needs of people living with Motor Neurone Disease (MND), Multiple Sclerosis (MS), Huntington's Disease (HD), and Parkinson's Disease (PD) and their families. The outcomes of the two-part study will be to recommend improved and supportive care systems.

The first phase of this study was completed in December, 2002 and involved interviews with people with these diseases and their carers, and with specialised health care professionals to ascertain the supportive and palliative care needs of individuals and family carers in these four illness groups.

The second phase is currently underway and involves a national survey based on the information obtained from the interviews. This survey will examine the extent to which the existing care system meet the needs of these people and their carers and the most appropriate models of supportive and palliative care for these individuals and their carers.

Developing Guidelines

Currently there are no guidelines for palliative care in residential aged care facilities (RACFs); no specifications for how aged care workers should be trained to provide such care; and no national education and training program. The Commonwealth Department of Health and Ageing commissioned the Australian Palliative Aged Care (APAC) team led by Professor Kristjanson and Associate Professor Kate White to address these issues. The APAC team includes a multi-disciplinary team of clinicians, researchers, leaders from the palliative care and aged care specialities from four different states. A consumer representative and coordinator of volunteers are also members of this leading team. A National Consultative Network has also been established through use of A



(Continued on page 10)



CURRENT RESEARCH

Mapping the Journey

Progress in medical technology and treatment has resulted in an increase in lifespan for people with many neurodegenerative conditions. This increased lifespan means that these individuals have a longer period of dependency on others with a heightened need to maintain quality of life for both the individual and the family. A study was conducted in collaboration with Edith Cowan University, Rocky Bay Inc, and the Motor Neurone Disease Association of WA on the needs of carers. This involved in depth interviews with sixteen carers to determine their perceived needs during the final stage of caring for someone with muscular dystrophy or motor neurone disease. The palliative care needs of these two populations and the supports that families required to guide them in their journey were examined. Results suggest that the palliative care model has much to offer individuals with degenerative neuromuscular conditions and their families, but it is not yet recognised as an important part of care for young people with MD. Three major themes emerged in the analysis:



Reactions and Responses: Health System Crossing Points: Reaching Forward. Results of this project are currently in press in the next issue of The Journal of Palliative Care.

Reactions and Responses: Health System Crossing Points: Reaching Forward. Results of this project are currently in press in the next issue of The Journal of Palliative Care.

PROFESSOR'S EYE VIEW

Palliative care in WA is characterised by a strong commitment to multi-disciplinary work and is enriched by expertise from dedicated medical practitioners, nurses, allied health professionals, and volunteers. This network of palliative care practitioners, researchers and service leaders has been actively working together during the past decade to develop innovative approaches to care and progressive educational programs. The clinical research groups within WA have begun to publish regularly in international refereed journals to advance knowledge development about palliative care science and the work of this community is becoming widely known and highly respected.

During the next few years, however, the palliative care community faces a number of challenging issues:

- ◆ How to meet the palliative care needs of a wider group of adults with non-cancer diagnoses?
- ◆ What are the needs of children with progressive illnesses and their families and how can these best be met?
- ◆ How to develop innovative and sustainable models of palliative care for rural and regional communities?
- ◆ How to more systematically offer palliative care within residential aged care facilities?
- ◆ How to best respond to the palliative care needs of people of various cultural groups?
- ◆ How to remedy the delays experienced by our patients for palliative radiation therapy? And How to undertake careful state wide planning to accommodate the needs of individuals who

(Continued on page 7)



(Continued from page 6)

are unable to manage in the community and require medium to long term palliative care support?

I am pleased to report that a number of initiatives are under way to address these issues, including a nationally funded study led by WA researchers and clinicians to develop palliative care guidelines for residential aged care facilities (www.apacproject.org). As well, a study to test a new approach to palliative care services in rural communities is being led by Associate Professor Kate White. Dr Leanne Monterosso is conducting a study of the palliative care needs of children in WA. And a project to assess the palliative care needs of individuals living with neurodegenerative disorders is nearing completion.



Professor Linda Kristjanson

The Palliative Care Advisory Group has given priority to the needs of individuals who may not be able to manage in the community and may require medium to long term palliative care and a working party led by Dr Doug Bridge is preparing a report on this issue.

A recent report released by the Clinical Oncology Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative (February, 2003) has identified the need for a National Strategic Plan for Radiation Oncology (Australia) to be implemented urgently, offering some promising direction for this care priority. A number of organisations within the WA community are concerned with the delays in access to radiation therapy treatments and a concerted effort to problem solve this issue is warranted.

And finally, a message to the palliative care community at this time of world unrest would be incomplete without an acknowledgment of the suffering that is presently occurring. As palliative care providers, the needs of those who are in distress, the reality of death, and the impact of grief and loss are all too familiar. Let us hope for a swift and peaceful resolution and be ready to call for a full and resonant humanitarian response.

Euthanasia for Belgium

Belgium is the second country after Holland to legalise euthanasia.

Palliation in Aged Care



Dr Chris Toye

Staff members at local aged care facilities have recently worked with Professor Linda Kristjanson and Dr Chris Toye from ECU, Ms Helen Walker and Ms Ellen Nightingale, from the Cancer Foundation's Centre for Palliative Care to develop a questionnaire to assess discomfort in aged care residents. A questionnaire previously developed by Professor Kristjanson for use with cancer patients has now been used with approximately 90 aged care residents able to report their symptoms and has been refined to meet the needs of this population. Results from this study indicate that the modified symptoms assessment scale is reliable, valid and appropriate for elderly people living in residential aged care facilities.



NOW ITS DR O....

As one of seven children brought up on a sheep station in WA, Lynn Oldham has come a long way. Taught by correspondence she coped with the distractions of a busy farm, especially around shearing time. Nursing was her choice of career and hospital-based training was at PMH. It was in 1985 that she decided on a change and found herself at the Queenslea Hospice, a pilot project set up by the Cancer Foundation which later transferred to the Cottage Hospice in 1987. Lynn loved the philosophy and impact of palliative care on the patients and their families and has been hooked ever since. Lynn was on the first team at the Cottage Hospice and was the Clinical Nurse Specialist when she left in 1996.

Lynn completed her Bachelor of Nursing (Hons) at ECU in 1993 and earlier this year was awarded her Ph.D. Her doctoral thesis, the first palliative care dissertation in WA, is entitled "Developing and testing a pain management programme for family caregivers of advanced cancer patients". Lynn is now at Doctoral Research Fellow and plans to continue contributing to the quality and availability of palliative care until she is at the least 95 !



Palliative Care For Children



Dr Leanne Monterosso

Palliative and supportive care services for children with life limiting conditions such as cancer are underdeveloped in the paediatric setting. There is an increasing awareness of the needs of these dying children and their families, however, there is a striking lack of evidence based literature on which to base paediatric palliative and supportive models of care. This study is the first of its kind in the area of paediatric supportive and palliative care in Australia.

This research will provide a broad and detailed description of the palliative and supportive care needs of families whose children died from cancer, as well as the types of care that may be required in the future. The study is addressing four research questions:

1. What are the supportive and palliative care needs of families of children who have died from cancer?
2. To what extent have the supportive care and palliative care needs of families been met in both the hospital and community settings?
3. How were the supportive and palliative care needs of families of children who died from cancer met?
4. What were the perceived barriers and facilitating factors associated with the supportive care and palliative care received by families whose children died from cancer?

This study, led by Dr Leanne Monterosso is the first of a four-phase research program that will culminate in the development and testing of models for the provision of palliative and supportive care for parents of children with life-limiting conditions in Western Australia.



WA's PRIORITIES

You can't get much closer to the coal face than three full time specialist palliative care physicians who spend their working hours in a variety of clinical settings looking after dying patients. And on top of that there's the teaching, the research and the admin. A busy life in palliative care as members of teams working in the Perth metro area and beyond. But what are the priorities for palliative care as they see them on the local scene?



Dr Doug Bridge of Royal Perth Hospital

- *Provision of beds in several sectors of the Perth metro area for patients with longer prognoses
- *At least 5 more specialists in palliative medicine. There is still extra capacity at RPH; a replacement for Dr Hilda Fleming who retires this year; a dedicated specialist at Fremantle Hospital; a third specialist at Hollywood and a second at Sir Charles Gairdner to support Dr Anil Tandon
- *Improved palliative care in nursing homes

Dr Sarah Pickstock of Hollywood Hospital's Palliative Care Unit

- *More palliative care beds for medium to long-stay patients
- *Improve the access to and availability of palliative care doctors both GPs who have a special interest and physicians
- *Improve the availability of palliative care drugs which allow more patients to be cared for at home.



Dr Anil Tandon of Sir Charles Gairdner Hospital

- *Improving the availability of palliative care in-patient facilities for patients with a longer prognosis.
- *Developing a shared-care approach to patients with Medical and Radiation oncologists.
- *Improving the access of Motor Neurone disease patients to in-patient and domiciliary palliative care.



PUBLIC FORUM

As part of the Palliative Care Conference and linking in with National Palliative Care Week a Public Forum is scheduled for Thursday 22nd May at the Hyatt Regency Hotel. The theme is Communication in End of Life Care which is to be presented by Professor Irene Higginson, Professor of Palliative Care at Guy's, King's and St Thomas' Hospitals in London. The time is 7.30 -9.30 pm. Entry is free. Palliative Care WA is grateful for funding provided by the Commonwealth Government to run this forum

(Continued from page 5) **Developing Guidelines**

A newsletter and the website to encourage wide community discussion regarding the guidelines. The draft guidelines were posted on the APAC website (www.apacproject.org) in Jan 2003 for public comment, prior to finalisation in May 2003. Additionally those people who registered via our website are being asked to participate in the development of competencies for aged care workers in residential aged care facilities by participating in an email survey. Once the competencies have been derived, a curriculum writer will develop an education and training program specific to palliative care for residential aged care facilities. Should anyone be interested in participating in this project it is not too late. Please go to the APAC website and register your details. The project team expects to deliver its final report by 31st December 2003. The project coordinator is Jayne Walton on 08 9273 8103 (h) or j.Walton@ecu.edu.au



Canadian Cannabis

Cannabis for use in a medical setting has been legal in Canada since July 2001. It is available under

certain conditions for people who have found that conventional treatments do not work and whose doctors have decided that its medical benefits outweigh its risks. Medical trials are now taking place in Holland funded by the government and there are four trials in the UK funded by the Medical Research Council. 2000 patients have been recruited into the trials.

NEW EQUIPMENT PROGRAM

Thanks to the Commonwealth Government's National Palliative Care Program there is approximately just over \$200,000 now available for new equipment grants in WA. Details as to how the grants will be made in WA are still being worked out but if your organisation is interested write and let us know. We can then send you the application forms as and when they become available. The equipment has to be used for the care of people who are dying in community settings. Equipment that is provided to the successful organisations will be made available on loan to palliative care clients whether they are at home or in an aged care facility. So - don't hesitate - if you are interested write to Palliative Care WA.

Founding Professor Dr. Irene Higginson

Irene Higginson the founding Professor of Palliative Care at Guy's, Kings and St Thomas School of medicine, Kings College London isn't afraid to tackle the controversial issues facing palliative care nationally and internationally. She is a member of the Royal College of Physicians in London and brings a wealth of experience in hospice work and community palliative care as the keynote international speaker at this weeks Palliative Care Conference being held at the Hyatt Hotel, Perth. An address to volunteers, a Public Forum and then three conference days make it a busy schedule for Professor Higginson whilst in Perth. Palliative Care WA is very grateful to her for sparing her time to participate in our conference. Prior to her current appointment Irene Higginson was senior lecturer in the Health Services Research Unit at the London School of Hygiene and Tropical Medicine and of Research and Development in Kensington, Chelsea and Westminster Health Authority. Prior to that she worked at St Joseph's Hospice, Hackney, University College, London; University College Hospital and the Bloomsbury Palliative Care team in London.

Prof:- Irene Higginson



GRIEF SUPPORT

There comes a time in our lives when loss and change may present many challenges and when a whole range of emotions may be experienced. This can occur following a serious illness, death of a loved one or any situation where a loss has occurred.

Silver Chain Grief Support Counsellors offer a range of services that promote healthy grieving and adjustment to changing circumstances. Families can talk with counselors who have the time to listen. This service is available to clients of Silver Chain's Hospice Home Care Service.

Also available is a range of children's programmes. "Blue Skies", "Stardust" and "Moonbeams" provide a safe, gentle and supportive environment for children to share together after someone has died in their family. Using puppets, paint, sand and music, children learn that it's ok to talk about their feelings and that with courage, patience and creativity they can have happy times again.

Grief and Loss education is also offered including a Support Skills Training Programme designed for professionals who want to understand grief and loss and increase their skills. The Silver Chain service is also available to bereaved family members at the Claremont Medical Centre. More information is available on 1300554122



Adjusting to changing circumstances.....

Palliative Care for heart failure

The patient of a palliative care doctor in Sunderland, UK said "What your team has been able to do for my brother with his lung cancer has been wonderful, tremendous. My family and I cannot thank you all enough – but why couldn't you have done the same for my wife when she had a stroke?" These words have been repeated in the British Parliament, at medical conferences and in medical journals as the push to extend palliative care into looking after end stage non-cancer cases gains momentum.

Most of the usually elderly patients with heart failure have short lives most often of poor quality, punctuated by frequent admissions to hospital. Despite some important advances in evidence based treatments, age adjusted survival rates for chronic heart failure remain worse than for many cases of cancer. The only cure for chronic heart failure – heart transplantation- is equivalent to providing one lifeboat on the Titanic. As one British TV programme described the scenario- "You're better off with cancer". They profiled the treatment received by Keith who had advanced colon cancer and Den who had end stage heart failure. The injustices in the disparity in the services were starkly reported. As one observer put it – "It was obvious that no one knew when to say STOP with increasing admissions to coronary care for Den and good quality palliative care for Keith" However, as the programme emphasized, meaningful specialized palliative care is far from universal for patients with cancer: those who receive it are still "the elite dying." However, nothing is straightforward, with the problem that predicting the illness trajectory is much harder in severe heart failure than in cancer. This creates uncertainty that can make it extremely difficult for doctors to make decisions, potentially preventing them from telling patients when they have reached the terminal phase of their illness and from planning appropriate care. In addition, there is the systemic problem that many palliative care services are under enormous stress just looking after mostly cancer patients. Any move to strategically plan to expand palliative care to other non-cancer cases would be welcomed by health professionals and health consumers but not without making sure that the proper structure, including funding and ongoing education were put in place.



LAST WORDS

An elderly terminally ill cancer patient who was admitted to hospital in Britain last year took exception to what he regarded as 'fussing' by the nursing staff. Late one evening his son Danny got a call telling him that his father was about to die. Unfortunately, Danny the son, didn't make it to the hospital in time. Seeing the look of disappointment on his face one of the nurses asked "Would you like to know your father's last words?" "Yes, of course" replied Danny. It appeared that his father had been comatose for some time but when they were changing his drip he opened his eyes and looked straight at them. "F*** off" he said, then closed his eyes for the last time. Certainly not poetic and probably on par with the immortal last words of George Vth – "Bugger Bognor". (The Lancet)



46 Ventnor Avenue
West Perth WA 6005
Phone/Fax 08 9212 4330
Email: pcwa@palliativecarewa.asn.au
Web: www.palliativecarewa.asn.au

KIMBERLEY PALLIATIVE CARE SERVICE

Kimberley Palliative Care Services have recently been revitalised through a new partnership between the Kimberley Health region and the Cancer Foundation Centre for Palliative Care. The new Kimberley Palliative Care Service is jointly funded by the State and Commonwealth Governments, and builds on work previously undertaken by Dr Jane Fischer, who left the Kimberley in 2000.

After Jane left, coordination of the service lapsed, however dedicated nurses and carers continued to provide services in spite of this setback. Over time however, the need for the re-introduction of a coordinating role was seen as essential to ensuring the most effective service provision possible. Wendy Scott has been appointed to the newly established Kimberley Regional Palliative Care Coordinator's position. Wendy will be based in Broome but will travel extensively throughout the Kimberley. A Management Committee has been established with representation from agencies and the community to guide the provision of services.

The KPCS has also secured additional funding from the Commonwealth Department of Health and Ageing to implement a Caring Communities Project. The name of this project is 'Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities' and will commence in June for 2.5 years. We hope to develop local support systems for people who wish to die in the 'country'.

The new address of KPCS is PO Box 62 BROOME 6725 P 91929295 or email Wendy at - wendy.scott@health.wa.gov.au.

We are very keen about our 'New Way Forward'.

NOTE: PCWA wishes the Kimberly team all the best!

COMMUNITY CARING

Funds have been allocated by the Department of Health and Ageing in Canberra for palliative care research. The following projects are being funded in Western Australia.

Fitzroy Valley Palliative Care Service	Nindilingarri Cultural Health Service Inc	\$57,890
Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities	Kimberley Health Region WA	\$64,000
Kalgoorlie-Boulder Palliative Care Coordination Project	Silver Chain Nursing Association Inc.	\$198,966
Learn Now, Live Well: An Educational Program For Patients And Care-Givers Living With And Affected By Life Threatening Illness	Ramsay Healthcare Australia Pty Ltd trading as Hollywood Private Hospital	\$162,870
South West Perth Collaborative Community Palliative Care Project	Murdoch Community Hospice Inc.	\$130,000