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EQUIPMENT PROGRAM - OPPORTUNITY KNOCKS BUT ONCE!

Earlier this year Palliative Care WA undertook responsibility to implement the Commonwealth Government's Palliative Care Equipment Program (PCEP) in Western Australia. Essentially, PCEP was a one off allocation of funds to assist the community to access equipment to support palliative care patients at home. The challenge to PCWA was to ensure that the \$216,400 allocated, benefited the public of Western Australia, while positively discriminating in favour of rural and remote communities' needs.

PCEP aims to improve the quality of palliative care in the community, with the specific objectives to:

- Support those who are dying to be cared for in the setting of their choice
- To improve the quality of life and dependence of those requiring palliative care in the community
- To promote equity of access to aids and equipment for those who are dying in the community
- To provide aids and equipment that are appropriate and cost effective to meet the identified needs of palliative care client.

A PCWA working group was established last year from palliative care services to spearhead the project and included an Occupational Therapist, Social Worker, Equipment Manager and Financial Officer to determine the needs and priorities for the greater West Australian region. Consideration of fund allocations included the presence of a dedicated palliative care service, number of patients seen, population served by the services and distance and isolation from Perth. Following an extensive consultation with palliative care providers in WA fund allocations were made. Successful applicants then identified equipment to the value of their allocation which was then purchased centrally resulting in significant volume discounts.

St John of God Health Care Bunbury.....	\$13,016
Homecare PCU Hollywood Hospital.....	\$14,510
Geraldton Palliative Care Service	\$15,887
Silver Chain Hospice Care Services	\$56,345
Pilbara Division of GP's PC Programme.....	\$22,861
Kimberley Regional Palliative Care Service....	\$25,709
Peel Community Palliative Care	\$16,741
Avon Hospice	\$11,740
Albany Palliative Care Service.....	\$15,032
Central Equip. Store inc costs for transport.	\$13,217
Kalgoorlie Palliative Care.....	\$7,322

TOTAL \$212,380



Stephen Carmody delighted at the thought of spending all that money while Shirley Glasgow does the hard work of sending it all out!

For areas where the palliative care need may be small or patients are infrequently admitted, additional funds have been allocated to a small central supply of equipment (held within the Silver Chain Care Plus equipment store). Limited funds have been quarantined to assist with the transport costs so that equipment can be delivered to patients' homes care saving a local service the worry of cleaning, storing and maintaining the equipment.

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The injection of funds is a wonderful opportunity for palliative care services to increase their capacity to enhance the independence of clients and their families who are living with a terminal disease. In the coming issues we hope to bring some stories of how this equipment has made a real difference to people's lives.



SUPPORT FOR MARIJUANA TRIAL



Palliative Care Australia has welcomed a NSW Government initiative to introduce legislation to allow a 4 year trial of the medical use of cannabis. The trial may well begin later this year. Palliative Care Australia's support is dependent on it being a properly evaluated clinical exercise, with specific measure of dosage and the type of patients who qualify as participants. Says Dr Paul Dunn Vice President of PCA "We welcome any progress in the use of medications or any innovation that improves symptom control or pain relief for people with a terminal disease".

Few patients in Tanzania have access to drugs in order to relieve pain. "Patients unfortunately have to endure pain in this country" says Dr Twalib Ngoma, Exec Director of one of Africa's main cancer centres, the Ocean Road Cancer Institute in Dar Es Salaam, Tanzania. Morphine only arrived in Tanzania and other African countries 3 years ago. However, says Dr Ngoma, "few patients can get access to morphine. It is a very emotional and disturbing experience for the patient, their relatives and the medical team. In most developing countries, because of a lack of drugs, pain is associated with cancer". Dr Ngoma and others in Tanzania are working to improve the medical care provided to patients who are terminally ill. "Unfortunately, the government has yet to make palliative care a priority" added Dr Ngoma.



The WA Government is in the final stage of preparing a discussion paper on planned end-of-life legislation. The State Solicitor's Office is preparing the document and in due course it will be circulated widely for comment. Later, it is hoped that legislation will be introduced that may enshrine palliative care in an act of parliament, give legal status to Living Wills or Enduring Power of Medical Attorney and perhaps make amendments to the state's criminal code in order that health professionals and carers do not face mandatory sentences of fifteen years for something they may or may not do in the best interests of a terminally ill patient. As soon as the discussion document is available copies will be made available to members of PCWA.



PCWA'S NEW EXECUTIVE COMMITTEE

Following elections at last November's AGM the following members of PCWA now make up the new Executive Committee:

Clive Deverall (President), Helen Walker (Vice President), Janette Newstead (Hon. Treasurer), Jenny Monson (Hon. Secretary), David Thorne, Stephen Carmody, Lynn Oldham, Helen Walker, Michael Bowran, Jenny Monson, Pru James and Sue Henning.

The following were noted as Chairs of the Sub-Committees: Standards & Quality - Terry Higgins and Clinical Issues - Valerie Colgan



We take this opportunity to thank Peta Firns for all her hard work and who decided not to stand for re-election and to Sister Teresa who stepped down earlier last year. We welcome our three new members, Sue Henning, Michael Bowran, Jenny Monson and just so you can put a face to their names here are some happy snaps and stories about them!

Michael has worked for many years in palliative care in both clinical and management positions. He started his WA PC experience at the Cottage Hospice and then spent several years working for Silver Chain Hospice Care Service, then Hollywood Private Hospital PCU, had a year in the emergency department at RPH and now, back at the Cottage. He completed his nursing training in Sydney where he worked for a short time then travelled to Nepal and the UK to work. He is currently completing post graduate studies at ECU in Health Services Management with a view to commencing a Masters degree in late 2004.

Sue (left) is a Support Manager at the Kingsley centre of the Silver Chain Hospice Care Service. She has been with Silver Chain for 15 years and for 8 of those with Palliative Care. One of Sue's roles is to manage and support staff to deliver services to Palliative care clients in the community. There are approximately 75 staff and 45 volunteers working from the centre including nurses, care aides, administrators, Doctors, counsellors, chaplains and volunteers.

Jenny (right) graduated as a social worker in 1971 and for most of her professional life has worked as a counsellor and psychotherapist. In 1989 she completed her Certificate in Palliative Care Studies, after which she joined with some local health professionals to form Bussleton Hospice Care Inc. Jenny chairs the management committee of the small hospice unit in Bussleton - a partnership between Bussleton Hospice Inc., Silver Chain and South West Health. She has her own counselling practice and does part time training work for Family Planning WA.



NATIONAL PALLIATIVE CARE WEEK 23-29 MAY 2004

The PCA Promotions and Marketing Committee gathered in Sydney in November 2003 to develop plans for National Palliative Care Week 2004. The agreed theme will be:- Caring for a person with a terminal illness. This theme picks up on PCA's strategic priority for 2003-2004 - improving for and recognition of carers who provide palliative care in Australia and in particular the partners, sons and daughters of those who are dying.



PCWA STANDARDS & QUALITY SUBCOMMITTEE



The Committee had an active and slightly volatile year last year. Penny Tuffin resigned as Chairperson in December 2002, with her last meeting being in February 2003. I took on the duties as Chairperson from that time with Susie Vojkovic taking on the tasks as Minutes Secretary. Ruby Robbins resigned for health reasons in February 2003. Jenny Jernakoff from Cottage Hospice joined the committee in March 2003, but had to leave us due to pressure of work in August 2003. Natalie Pannizza from Royal Perth Hospital joined us in March 2003. Unfortunately, Angie Spaziani resigned in July 2003 due to pressure of work and the demands of further study. However, we were pleased to welcome John Neale to our ranks in September and looked forward to Rita Paglia joining us in December. John is a volunteer at Murdoch Community Hospice and Rita is a pastoral care provider from St John of God Subiaco.



In the view of the turnover of committee members, it has been decided that an orientation package should be prepared. This will be provided to all new members so that they receive some orientation on the goals of the committee and information about our members. The package will include the Terms of Reference, a printout of a Power Point presentation describing the structure and relationships of PCWA and PCA, a copy of the Palliative Care Standards and brief notes about each committee member. I am grateful to David Thorne for sourcing the Power Point presentation and to Susie Vojkovic who is putting the package together.

During the year the committee followed up on its initial survey of rural palliative care providers, which was undertaken to try and ascertain how the Standards & Quality committee could be of help to them. The report was distributed to rural services in February. Those services which did not have a copy of the Palliative Care Standards Book were advised how to download the standards from the PCA website. Several services had not received a SASA disk from PCA and it appeared that this was because they were not registered with PCA as palliative care providers. All rural providers were advised to do this.

Further work involved the development of the Palliative Care Service Evaluation Survey. This is the version of the FamCare Survey which is deemed to be a reliable and validated survey tool. The committee thanks Linda Kristjanson for her help in identifying the most appropriate and reliable version of this survey for us to recommend. Each rural palliative care service was sent a letter explaining the advantages of such feedback from client's families, how the survey could be used and a copy of a covering letter which could be sent out with the questionnaire. It was also explained that Edith Cowan University Centre for Palliative Care Research is willing to collate and analyse the data and how to send in the completed questionnaires. ECU will charge a small fee for this service. It is hoped that an analysis of aggregated data from rural services will help us identify areas in which this committee can be of assistance to such services. I would like to thank PCWA for the support and assistance that has been given to us throughout this project. Particular thanks go to Heather and Mary for their work in doing the necessary mail outs.



There was a plan to present a workshop about the Palliative Care Service Evaluation Survey at the State Conference. Unfortunately, this did not eventuate; but we were able to have a stand at the conference and we distributed over 40 packs of information. We were also able to talk to a great many people from rural areas of the advantages of using such a survey. We consider that our booth was very successful. Again, I thank PCWA for their assistance. A follow-up letter has recently been mailed out to all the services to which we sent the Survey packs, asking for feedback. Mary did a great job at tracking down the mailing list. For the forthcoming year it looks as though this committee will be kept busy with assisting in the reviewing



of the Palliative Care Standards. David Thorne, as the new Chairperson of the PCA Standards & Quality Committee, has offered our services in this significant task. We commenced a literature search relating to palliative care standards world-wide, and have become aware that there is a great deal more information available now, than there was when PCA first commenced work on the current Standard. PCA have also informed us that there may be Commonwealth funding available in order that all health service standards be presented with a common format. We are waiting to hear where we go from here.

It has been an interesting year and I most sincerely thank all the members of this committee for their commitment, dedication and input. It is not always easy to turn up for yet another meeting but these people do so regularly and cheerfully. The aim is always to try and identify how we can improve palliative care services to people all over Western Australia.

Terry Higgins - Chairperson

WHAT IS LIFE?



Dull or exciting, life lasts around 600,000 hours for men and 700,000 hours for women. That is if you don't have a serious illness or an accident and die. So how many hours do you have left? Half a million? Six hundred thousand - 3000 weeks? If it's half a million hours you'll spend a third of that horizontal - asleep. You may, with the increase in early onset dementia, lose thousands of hours in a daze...and then there's the hours lost washing up, cleaning or going to the shops. And the interminable television where you can both watch it and remain asleep at the same time. Then the computer, which saps more and more time from an earlier and earlier age. Add the traffic jams, the airport check-ins, queues of all types, preparing BAS statements and the theme of that line in a song

"Stop the world I want to get off" - begins to make sense!



HOW CONFUSING!

You've no doubt heard how some health professionals from overseas who are struggling to learn this complicated language called English find it difficult to cope with heroin and heroine. Even if English is your first language it wasn't helped by a recent edition of the St Michael's Parish Church bulletin in Daceyville, NSW which ran the following: RECENTLY DECEASED: We sadly announce the death of - xxx - at the Sacred Heart Horse Peace. And as one Australian tells the story of his visit to the hospice in Tokyo, called the Peace House, built with the help of West Australians, "Be very careful with the pronunciation!"





PEEL COMMUNITY PALLIATIVE CARE

Peel Community Palliative Care assumed full responsibility for the delivery of care to palliative clients in the Peel Region on 11th April 2001. The service initially had 17 home based clients. It has grown to 47 clients today, also offering a bereavement follow up to a further 45 families.

Peel Community Palliative Care provides specialised palliative home care and support for clients and their carers/families. The service is based at Murray District Hospital, Pinjarra. The extent of the region covered by the service is seven postcodes - 6207, 6208, 6210, 6211, 6213, 6214 and 6215. Population of approximately 90 000. Area of approximately 6,500 square kilometres. Support is available 24hrs a day, seven days a week. The team consists of clinical nurse manager and registered nurses, all experienced in palliative care.



L-R Gill Abbiss (CNM), Canon Ken Barrett (Chaplain), Maureen Bowlay (RN), Fran Paverd (RN)

Three palliative care consultants joined the team in 2003, Dr Kirsten Auret, Dr Sarah Pickstock and Dr Liz Whyte - visiting the Peel region on a rotational fortnightly basis. The consultants provide home visits for clients, support and education is offered and available to local General Practitioners and other groups.

The local GP remains the pivotal person in client care and close liaison with them is imperative. The client and their carers are the focus of care. Quality of life, as determined by the client, is the priority. A Chaplain is also part of the team and makes contact with clients and families. Recent recruitment of volunteers has occurred adding another branch to the service.

The service has also met criteria and obtained a Veteran's Affairs contract, this initially ran from June 2001-June 2002. This has recently been renewed for a further two years. The service is providing education for other health professionals and other health services.

A range of equipment is available for clients to use at home. Numerous ongoing quality activities have occurred and have been reported on to ensure clients, carers and referring agencies needs are being met and any issues addressed. The focus being at all times on providing the highest quality palliative service to all consumers.

Peel Community Palliative Care is funded by the State Government.



A TIP!

‘What to say when you think its your turn: “Stop talking when I’m interrupting” (Alan Jones)



RECORD NATIONAL CONFERENCE

1006 people attended the National Palliative Care Conference held in Adelaide in September 2003 - including 82 from overseas. With significant financial support from the South Australian Government and the Australian Government also making a financial contribution together with pharmaceutical industry sponsorship the Conference was a resounding success in terms of interest, value for those attending and a positive financial outcome for the organizers the South Australian Palliative Care Council led by Dr Mary Brooksbank. Well done to all those who worked so hard behind the scenes and those WA presenters, one of whom presented multiple papers.

UK MISSION TO IMPROVE CARE FOR THE ELDERLY

Dr Katherine Froggatt is a MacMillan funded Senior Research Fellow and Head of the MacMillan Practice Development Unit at the University of Southampton. She has been touring Canada and Australia to examine how palliative care is provided for the elderly, especially in nursing homes. "We realize we have an ageing population and I hope to use the knowledge and experience I gain to help develop better care for terminally-ill older people in the UK and to establish a network of people interested in developing the provision of this care" says Dr Froggatt. Only last year a discussion paper released by the UK based King's Fund said the National Health Service was failing to provide adequate emotional or practical support for the terminally ill. In Canada, a National Guide for End of Life Care for Seniors was released in 2003.

ACCURATE REPORTING!

US Secretary Donald Rumsfeld scooped the Plain English Campaign's annual "Foot-in-Mouth" trophy with this 62 word attempt to clarify a point at a US Defence Department meeting. The master of obfuscation said: "Reports that say that something hasn't happened are always interesting to me, because as we know, there are known knowns; there are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns — the ones we don't know we don't know." Campaign spokesman John Lister said, 'We think we know what he means. But we don't know if we really know...'

Now - just to think, some years back we had a Commissioner for Health who was equally confusing (sorry - no prizes, Ed)



David Currow the President of Palliative Care Australia who holds the Chair of Palliative Care & Support Services at Flinders University in South Australia was the guest speaker at Palliative Care WA's AGM held at St John of God Hospital, Subiaco on 25th November 2003. David focused on the problems facing palliative care nationally with some interesting comparisons with what has been happening internationally. The expansion of palliative care for non cancer conditions, said David, is a welcome challenge which must be accepted and well managed with appropriate structural support including proper funding from government at all levels. **David has also recently been elected - President Elect of the Clinical Oncological Society of Australia - a first for a palliative care doctor.**



WEST AUSTRALIA PALLIATIVE CARE CONFERENCE - 2004

For your diary! This year The West Australia Palliative Care Conference is being held on the 9th & 10th September at Joondalup Resort.

"PALLIATIVE CARING AT HOME" BOOKLET

This superb little booklet helps carers through the complexities of caring for a person with an advanced and terminal illness. If you would like a copy of "PALLIATIVE CARING AT HOME" they are available for \$3.00 per copy plus p&p.

Please contact:- Palliative Care WA (Inc) 46 Ventnor Avenue, West Perth, WA 6005
Tel: (08) 9212 4330 E-mail: pcwainc@palliativecarewa.asn.au



VOTE LIBERAL! - Anything they review we'll review better!



VOTE LABOUR! - The contractions are over; look forward to the birth of a new to-morrow!



PLEASE REMEMBER!!!

We are a very small organisation with a part time administration person working 12 hours a week at \$13.00 an hour. Our office is provided on a grace and favour basis by the Cancer Council Western Australia. Our financial resources are limited with the major source of income being members annual fees. Some project funding is occasionally provided by service providers and/or pharmaceutical companies. Your continuing support as a member is very valuable to us.

SO PLEASE! Help our Association grow and introduce a new member today!

