



Palliative Care WA (Inc)

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**22 - 28 MAY, 2005**

**National Palliative Care Week**  
Partners in caring

**2005**



What is **palliative** care?

Visit [www.pallcare.org.au](http://www.pallcare.org.au)

or call 1800 660 055

## CHOICE IS THE KEY

The Australian Government is providing \$201.2 million throughout the five years of the Australian Health Care Agreements (2003-2008) for palliative care. Of this, \$188 million is broadly allocated on a per capita basis to the state and territory governments for continued service provision, and \$13.2 million for the Australian Government to implement a national program of initiatives. In the 2002 Federal budget, the Australian Government announced a further \$55 million over four years (2002-2006) for national activity to improve the standard of palliative care offered in local communities. The combined national allocation of \$68.3 million (2002-2008) comprises the National Palliative Care Program, and is being implemented across six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community
2. Assistance for families and increased support to other care networks
3. Education, training and support for the primary care workforce
4. Increasing the range and reach of palliative care services
5. Capacity building in the palliative care research community
6. Performance information development

Underpinning the National Palliative Care Program is the National Palliative Care Strategy (the Strategy) endorsed by the Australian Health Ministers' Advisory Council in October 2000. The Strategy represents the commitment of the Australian and state and territory governments to the development and implementation of consistent palliative care policies, strategies and services that are accessible to all people who are dying.

A key premise under the Strategy is that palliative care must form an integral part of a comprehensive health care system that supports people at all stages of life, helping people to die well in an atmosphere of care and support. The Strategy respects as part of this the central **importance of choice** – regarding the setting of care, the manner and type of care provided.

It is important to note that under the National Palliative Care Program, the Australian Government's principal role is to coordinate and support national initiatives which support the objectives of the Strategy with the aim of improving the quality of and access to palliative care in Australia. A key consideration in developing this initiative is the involvement and advice of state and territory governments, the community and other key agencies and groups in planning and conducting national projects and activity.

Further information on the National Palliative Care Program is available from the National Palliative Care Program Website at <http://www.palliativecare.gov.au>

## PALLIATIVE CARING AT HOME BOOK

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/Fax: (08) 9212 4330  
E-mail: [pcwainc@palliativecarewa.asn.au](mailto:pcwainc@palliativecarewa.asn.au). Please leave a message if the office is unattended.

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## ***ACTION BY THE MINISTER***

Attorney General Jim McGinty who is also the Minister for Health has confirmed to PCWA, in writing, that his Government wishes to move on legislative reform relative to End-of-Life legislation – before the year ends. In his letter he states that he is in the process of finalising a discussion paper –“which I will provide to you (PCWA) for consultation by the end of this month (April)”. He goes on to state that the discussion paper will address mechanisms to implement advance health care planning, consider options for reform and make a number of recommendations. And finally “In consultation with Palliative Care WA (Inc) and other interest groups, I intend to work with the Parliamentary Counsel’s Office to properly craft legislation so that the wishes of a dying person are respected”. This is great news for PCWA taking into account our lobbying for legislative change since 2001. As soon as the discussion

paper is available copies will be circulated to members for their input. A great start to Palliative Care Week 2005 in WA.



***The Hon Jim McGinty***

## ***PALLIATIVE CARE WEEK 2005***

May 22 - 28th is Palliative Care Week. It's a national event which is financially supported with small grants from the Australian Government and Palliative Care Australia. Also helping on a state basis are A H Crawford Cancer Treatment Society, Silver Chain Hospice Care Service, The Cancer Council Western Australia, Murdoch Community Hospice and The Dept. of Health. And this year it's off to The Zoo for the traditional Palliative Care Week Breakfast launch at 7 am on Monday 23rd. Tickets are a bargain at \$20 and \$15 for Palliative Care Volunteers. So please bring yourselves plus a work colleague or someone who might be interested in hearing from the Minister for Health, Jim McGinty, about the planned health reforms and how they will impact on palliative care and, we hope, planned new end-of-life legislation. Whatever your interest or involvement in palliative care its also a great opportunity to meet friends and colleagues you may not have seen for some

time. Other events are being held during palliative care week will be in Perth suburban and country WA. Media coverage will focus on the recurring theme of “Partners in Caring”. This picks up on 2004 when the results of research into the burden that carers of terminally ill patients have to carry was released nationally and in Perth. PCWA also formally affiliated with Carers WA in acknowledgement of the common issues being dealt with by both organisations. Many patients express their own concerns about how they are a burden to their own carers and the need for carer support. So, Perth Zoo Function Centre at 7.00 for 7.30 am on Monday 23rd May – in Labouchere Road, South Perth.

***There is plenty of parking. BUT YOU NEED TO BOOK!***

***Email: [pcwainc@palliativecarewa.asn.au](mailto:pcwainc@palliativecarewa.asn.au) Fax: (08) 9212 4330***

***Please phone Pru James on 0418 903337 or Jannette Newstead (08) 9382 3774 (day time) for more details. See you there!***

***Left: PCWA Administration Co-ordinator Mary Thornton gets ready for Palliative Care Week 2005!***



## NEW GOVERNMENT & PALLIATIVE CARE

Geoff Gallop's government has been returned and Jim McGinty carries on with the Health portfolio as well as Attorney General – a formidable burden. That's probably good news for the health sector at least in terms of continuity following the endorsement of the Reid report, the departure of the Director General Mike Daube and Neal Fong being appointed in his place, albeit in an acting capacity. Dr Fong continues to manage the implementation of the Reid recommendations which will impact on the provision of palliative care services. Dr Fong has appointed a senior executive in his Reid implementation team with special responsibility for palliative care. The State Palliative Care Advisory Group has also been kick started

into action as described by Professor Linda Kristjanson in the last PCWA Newsletter. The non government sector is also pleased with the revised funding arrangements for the care of public, uninsured patients. It only took 9 years of stubborn lobbying by the organisations concerned plus PC WA but, at long last, the state health department agreed to increase the funding to a realistic level. All this looks positive for palliative care in WA. There will be systemic change but hopefully with a positive horizon, the mid to long term outcomes will be of more benefit to the community as a whole. Tied in with this state level activity is a national focus on cancer treatment services. A Senate Inquiry has been initiated by Senator Peter Cook, (from WA) who was recently diagnosed with cancer, into the country's cancer treatment services including access to

complementary therapies. There will be public hearings held throughout the country and a report published in June. At the same time the Australian Government has committed several millions of dollars to set up "Cancer Australia" with the objective of re-organising all the different aspects of cancer prevention and treatment, including palliative care. And following the election in WA, the Green's (Robin Chapple) Euthanasia Bill has expired. There will be no more debate in either the Upper or Lower House. Now is the opportunity for the Labour Government to take the initiative and introduce much anticipated End-of-Life legislation. There is a precedent for support from all sides of politics following the passing of the Carers legislation at the end of last year.



## NEW PALLIATIVE CARE INFORMATION GUIDES

Three new information leaflets have been produced by PCWA. These consist of a basic Information Guide outlining palliative care advice and facilities, and a card and bookmark listing services available within WA. Our aim is to distribute these throughout WA via doctors and pharmacy outlets for the general public.

If you are able to help distribute brochures to your local pharmacy or doctors, please email [pcwainc@palliativecarewa.asn.au](mailto:pcwainc@palliativecarewa.asn.au).

Many thanks to all those wonderful people who have helped us so far!

**PEPA**  
**(Program of Experience in the**  
**Palliative Care**  
**Approach)**

PEPA gives the opportunity for both metro and rural primary health providers, who in their work role care for people at the end of life, to complete a supervised clinical attachment in specialist palliative care services. PEPA is a funded program with no cost to successful participants. There is funding to "backfill" the positions of successful applicants so that they may continue to be paid while on placement. Funding also covers travel and accommodation costs for rural participants.

PEPA has been implemented in two stages. The first stage (PEPA 1) targeted rural and metropolitan nurses, allied health professionals and care assistants. By March 2005 twelve people had successfully completed a 10 day clinical PEPA 1 experience. The second stage (PEPA 2) provides General Practitioners and rural and remote medical officers with the opportunity to complete a 3-5 day supervised clinical attachment in metropolitan palliative care services. There is also an opportunity for health professionals working in specialist palliative care doctors to broaden their experience by undertaking a clinical attachment with other specialities.

Western Australian is fortunate to have a range

of palliative care services that have offered a rich experience for PEPA participants. PEPA will continue until 30 April 2006.

**National Indigenous Palliative Care Guidelines Project**

In addition, the Palliative and Support Care Professional Development Centre is coordinating a project that provides non-indigenous health professionals with an opportunity to develop skills in culturally appropriate palliative care of Indigenous Australians.

A national resource kit "Providing culturally appropriate palliative care to Indigenous Australians" is available on request. The kit comprises of information pertaining to the palliative care of Indigenous communities, including their cultural needs and practical principles for health care providers to adopt. To complement the resource kit, the Professional Development Centre project team are developing a directory of local resources and training packages adapted to local needs.

***If you would like any further information on the above programs please contact the Palliative and Supportive Care Professional Development Centre on 9382 3774 or [helenwalker@cancerwa.asn.au](mailto:helenwalker@cancerwa.asn.au) or [Fcooper@cancerwa.asn.au](mailto:Fcooper@cancerwa.asn.au)***

**L - R**

***Janette Newstead,  
Anne Thompson,  
Fran Rush,  
Ann Geling,  
Tina Watkins,  
Felicity Cooper,  
Helen Walker  
Pamela Heath(Seated)***

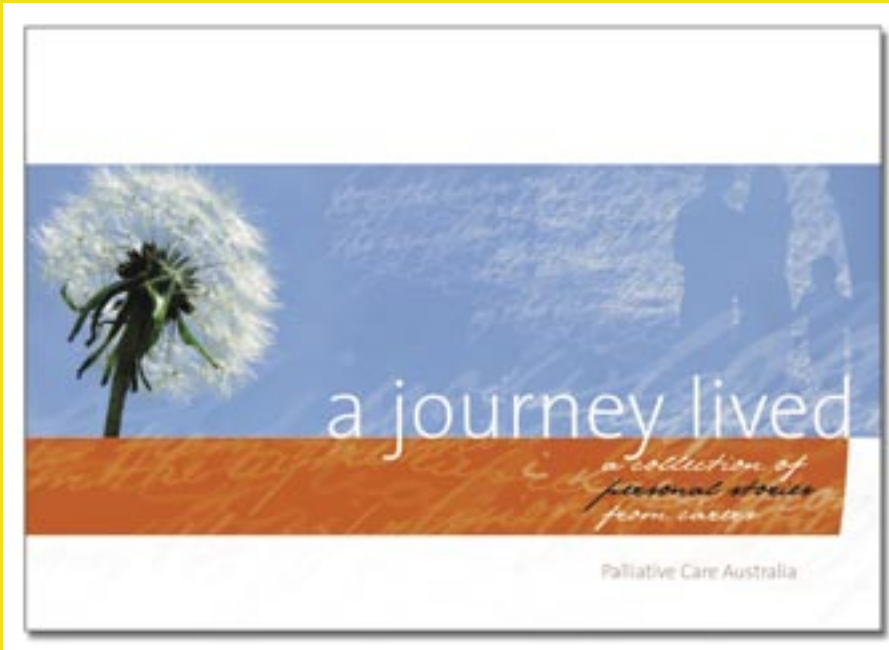


## WHO SAID THAT?

*The old believe everything; the middle aged suspect everything; the young know everything.  
Oscar Wilde (1854-1900)*

## A JOURNEY LIVED

In the lead-up to National Palliative Care Week, Palliative Care Australia (PCA) have launched a publication that aims to increase community awareness of palliative care and highlight the fantastic support services available for terminally ill people and their carers. It will also pay tribute to all the carers who make such a significant contribution to the care of terminally ill people in Australia.



*"We are delighted with this publication and are particularly grateful to those who contributed their stories, opening their hearts and, for some, old wounds to share their personal experiences with other caregivers," PCA President Professor David Currow said.*

*"For people who are faced with caring for someone with a life-limiting illness, it is essential that information is readily accessible and*

*understandable. Being able to read the stories of real people will remind them that whilst their situation is unique they are not alone*

*"This publication highlights the philosophy of palliative care, which aims to affirm life and regards death as a normal process. It then seeks to educate the community on care options for those who have reached this stage in their lives."*

For further information or to obtain a copy of A Journey Lived or to find out more about National Palliative Care Week activities during 22 - 28 May 2005, visit the Palliative Care Australia website at [www.pallcare.org.au](http://www.pallcare.org.au) or call 1800 660 055

## WHAT A ROTTER!

The Prescription Pricing Authority in the UK now allows GPs to prescribe sterile maggots of the common greenbottle (*Lucilia sericata*) for the treatment of infected and necrotic wounds. The maggots even have a branded trade name – LarvE and are produced by the million in Bridgend, South Wales by a company which is part of the NHS Trust.

**PCWA ANNOUNCE THE LAUNCH OF  
NATIONAL PALLIATIVE CARE WEEK 22 - 28 MAY 2005**

**By The Hon. Minister for Health**

**Jim McGinty**

**PALLIATIVE CARE WEEK BREAKFAST**

**At:** The Perth Zoo Function Centre  
Labouchere Road  
South Perth

**When:** Monday 23 May 2005

**Time:** 7.00 am for 7.30 am Start  
Until 9.00 am

**Cost:** \$20-00 per person  
\$15-00 PC Services Volunteers

To register please email the PCWA office on [pcwainc@palliativecarewa.asn.au](mailto:pcwainc@palliativecarewa.asn.au) or Fax(08) 9212 4330. For further information on PCWA Breakfast please contact Pru James 0418 903337 or Janette Newstead (08) 9382 3774 (daytime)

Alternatively please forward a cheque, money order or credit card details to:

Mary Thornton, PCWA (Inc),  
46 Ventnor Avenue, West Perth,  
WA 6005

Please include your name, address and contact phone number and a ticket and receipt will be forwarded on to you.

Cheques made payable to Palliative Care WA (Inc)



## **PAEDIATRIC PALLIATIVE CARE RESOURCE PROJECT**

### ***Palliative Care Australia***

#### ***Background***

In 2003 the Australian Government's Department of Health and Ageing, as part of the National Palliative Care Program, commissioned a study which examined the ways in which paediatric care is delivered in Australia. The Final Report was published in January 2004. Amongst a range of recommendations the Report called for the provision of "comprehensive and timely information about both the clinical and management aspects of paediatric palliative care...to provide support to families (particularly in rural areas), local health care professionals, community hospitals and other relevant organisations".

#### ***Project Details***

As a direct result of this recommendation Palliative Care Australia was contracted by the Australian Government Department of Health and Ageing to develop a national resource guide for paediatric palliative care. This resource will be targeted towards carers of paediatric palliative care patients, particularly those in rural

and remote areas. It will provide reliable information about quality resources, clinical and social support services available both at a national and state level. The aim of this project is to maximise the accessibility of existing resources and services particularly to those people living in rural and remote areas.

The priority of the Paediatric Palliative Care Resource Project (PPCR) is to make sure that the resource is of high quality, accessible and consumer focused. To achieve this the project is being developed with the ongoing assistance of a Project Reference Group consisting of specialist paediatric palliative care clinical service providers and consumer organisations and a Carers Reference Group consisting of carers from both rural and urban locations.

A comprehensive Consumer Consultation has also been conducted. This consultation found there was a strong desire for both a written and web based paediatric palliative care information resource, but that the need for a quality written resource was more immediate. Consequently the decision was made to produce a hard copy resource guide in a format that can

be easily updated and distributed. It will also include brief summaries of key issues, advice on questions to ask, checklists on things to be thinking about, lists of other quality resources, services and information available in regional areas and some carers stories

The Project is now at a very busy and creative stage. The first draft of the resource is currently in development. The Project Reference Group is working extensively in assessing existing resources for inclusion in the PPCR and the Carers Reference Group is providing invaluable expertise on its format and content.

The Paediatric Palliative Care Resource will be produced both as a hard copy folder and in electronic form and is due to be released at the 8th National Australasian Palliative Care Conference in Sydney at the end of August 2005.

For any further information or to provide feedback please contact:

***Sarah Jones***  
***Paediatric Palliative Care***  
***Resource Project Coordinator***  
***Palliative Care Australia***  
***PH: 02 6232 4433***  
***EMAIL: sarah@pallcare.org.au***

## **EUTHANASIA IN UK**

For the first time a credible authority has put a figure on 'assisted dying' rates in the UK. Dr Hazel Biggs, director of Medical Law at the University of Kent and author of the report *Euthanasia: Death with Dignity and the Law* revealed that at least 18,000 people a year are helped to die by doctors who are treating them for terminal illness. The report has been submitted to the House of Lords which is examining a private member's bill on Assisted Dying for the Terminally Ill. It has also been taken up by the European Journal for Health Law. Pro-euthanasia campaigners have seized on the report in support of their calls for changes to the law so that health professionals can help conscious, terminally ill patients whose pain cannot be adequately managed to shorten their lives. Dr Biggs says that "We know

what is happening but it is all unregulated. We don't know how many people volunteer their consent or are non-volunteers. The laws need to be changed so that patients can be properly protected". Current UK opinion polls show overwhelming public support for changes to laws that will make it easier for terminally ill patients with complex pain problems to request medical help to shorten their lives. Approximately 80% of people participating in the opinion polls support changes to the laws. Politicians from the major parties have consistently deflected moves to change the law on euthanasia, believing it is unlikely to be a vote winner. If the current bill being considered by the House of Lords is passed it will then be debated by the House of Commons. A select committee representing the Church of England and Roman Catholic Bishops vigorously oppose any change.

## **CANCER AND PALLIATIVE CARE: SHARING OUR PRACTICE**

### **THE UK EXPERIENCE by Dame Gill Oliver**

PCWA and WACOG hosted a lively seminar presented by Dame Gill Oliver at SJOGH early in March.

Gill talked about her role over the last five years as Director of Service Development for MacMillan Cancer Relief, a major UK cancer care charity and discussed the expansion and development of MacMillan services for people affected by cancer. Her positive “can do” approach was reflected in her closing quote attributed to Sara Henderson.

***“Don’t wait for someone else to light the candle at the end of the tunnel - get down there and light the \*\*\*\* yourself.”***

Gill also gave two keynote presentations at the Cancer Nursing Research Conference that was held later in the week. In her first keynote address “Bringing Research to Life” Gill commented on how little (research) resource is directed to palliative care and to qualitative, holistic and patient focussed studies in the UK. She highlighted the importance of involving consumers of cancer services in all aspects of service development and provided examples of how this had been accomplished. She demonstrated the influence that both service consumers and health care professionals have brought to bear on the national cancer and palliative care research agenda. This

included supporting consumers to take an active part in developing and promoting research. Gill’s second keynote address “ Shaping the Future of Nursing” explored the potential role of the nurse of the future and described ways to contribute to the expansion and development of excellent and expert care in cancer and palliative care nursing.

Gill made an enormous contribution to cancer and palliative care during her brief time here. She was generous with her time and knowledge and I believe that our community has been enriched by her enthusiasm and expertise.



***Dr Lynn Oldham, Prof Linda Kristjanson and Dame Gill Oliver***

### **ANOTHER \$56,000 FOR EQUIPMENT**

PCWA has just distributed another \$56,000 worth of equipment to assist provision of better palliative care in 12 aged care services, primarily in regional WA. This follows on from grants of \$250,000 made last year, all with the assistance of the Dept of Health & Ageing in Canberra and Palliative Care Australia, also based in Canberra. Said one recipient “The equipment we bought with the PCWA grant really helps us in a practical way as our operating budget could not stretch to make such a purchase. The equipment will help numerous patients over time”. Amongst the 12 recipients were Clarence Estate, Albany, Yulanya Nursing Home, Port Hedland, Leeuwin Lodge, Augusta, Gwen Hardie Lodge, Albany,, Sandelwood House, York and Springhaven Lodge in Kojonup. A happy ending to the collection and distribution of taxpayer’s dollars!

***Right: Sue Henning, PCWA Executive Committee Member organised the distribution and purchasing for the Equipment Program***



## **PALLIATIVE CARE ADVISORY GROUP**

### **Report Number 2**

I am pleased to provide this second report on the work of the Palliative Care Advisory Group (PCAG). As you recall from the previous PCWA Newsletter report, a project is underway to provide direction for state palliative care services for the future.

**Liaison with Health Reform Implementation Taskforce**

We are working closely with Mr Clory Carrello, Department of Health and Mr Kingsley Burton, a representative of the Health Reform Implementation Taskforce to develop a State Palliative Care Plan and to move forward on the recommendations related to palliative care outlined in the Reid Review.

#### **Project Steering Committee**

A Steering Committee from PCAG has been appointed by Dr Neale Fong to guide the project. These members include: Dr Anil Tandon and Mr Gareth Griffiths from Sir Charles Gairdner Hospital, Mrs. Eleanor Roderick from Murdoch Community Hospice, Mr Steve Carmody from the Silver Chain Hospice Services, Ms Amanda Leigh from The Cancer Council Western Australia, Dr Lorna Rosenwax from the Faculty of Medicine and Dentistry at UWA and Dr Scott Blackwell, who is associated with both Silver Chain and Cottage Hospice. As well, the Steering Committee is liaising with the full PCAG group related to the overall direction of the project and specific issues that warrant expert input (eg. rural palliative care issues, paediatric palliative care).

#### **Progress-to-date**

A call for submissions was sent out at the end of February 2005 to the health care community requesting comments and written submissions on issues pertinent to the review. This call was made to ensure that all individuals within the State who might have a viewpoint related to the project would have an early opportunity to contribute. We have already received a number of submissions from individuals, organisations and groups of health professionals who have provided very helpful comments and insights into the future needs for palliative care service delivery.

Interviews with key stakeholders have also begun and focus group meetings with groups of palliative care providers and health care providers have started. These include videoconferencing with rural and regional groups to ensure a wide representation of viewpoints and experiences. We will also be holding interviews with specific sectors in the health care system that may have special needs related to palliative care (ie, Motor Neurone Disease, aged care, paediatric care, etc) and also with consumer groups. The information from these interviews will help the project team to understand unique factors that may be influencing palliative care delivery, and future directions in various sectors and locations within the State. These perspectives are essential to ensure that recommendations arising from the project will be sensitive to real-world clinical concerns and service delivery parameters.

The project team is also reviewing recent reports regarding the palliative care services, needs and programs. As well, information regarding existing palliative care clients and service utilisation is being obtained in conjunction with data regarding projected population growth and distributions within the State. This will be essential to anticipating the future needs of palliative care populations.

#### **Next Steps**

- The results of the interviews, review of reports and population data will be synthesised to arrive at a draft model(s) for palliative care delivery within WA.
- These draft models will then be presented to focus groups and key stakeholders within the State to ascertain the feasibility, suitability and merit of the various approaches.
- Revisions based upon feedback from interviews and focus group meetings will be incorporated.
- Recommendations will be made via the Steering Committee to PCAG and the Health Reform Implementation Taskforce to ensure that the project stays well linked to strategic decision points in the health reform process.

The project is moving at a fairly brisk pace; however, the response from the community has been extremely constructive in assisting the project team to obtain the relevant information needed.

### ***Project Staff and Input Opportunities***

Dr Samar Aoun is the Project Manager for the team and has been busy conducting interviews and meeting people within the palliative care community. She is supported by Mrs Jayne Walton, who is assisting with collation of reports and information as submissions arrive. They can be contacted on s.aoun@ecu.edu.au (0419911940) or j.walton@ecu.edu.au (08 9273 8108).

The Project Steering Committee would welcome any queries or thoughts on the project and look forward to keeping you informed of our progress. I can be reached personally on the following e-mail and number (l.kristjanson@ecu.edu.au or 08 9273 8617).

Please contact us with your submissions or comments. This is an important opportunity to help guide the development of palliative care services for our future and we welcome your input to help ensure that we get this right.

And finally, I would like to personally thank the members of PCAG and the Steering Committee for their invaluable assistance in guiding this work.

***Linda J Kristjanson - The Cancer Council WA Chair of Palliative Care & Chair, PCAG***

### ***DICKSHINARY!***

***Once again, The Washington Post has published the winning submissions to its yearly contest, in which readers are asked to supply alternate meanings for common words.....And the winners are:***

1. Coffee (n.), the person upon whom one coughs.
2. Flabbergasted (adj.), appalled over how much weight you have gained.
3. Abdicate (v.), to give up all hope of ever having a flat stomach.
4. Esplanade (v.), to attempt an explanation while drunk.
5. Willy-nilly (adj.), impotent.
6. Negligent (adj.), describes a condition in which you absentmindedly answer the door in your nightgown.
7. Lymph (v.), to walk with a lisp.
8. Gargoyle (n.), olive-flavored mouthwash.
9. Flatulence (n.) emergency vehicle that picks you up after you are run over by a steamroller.
10. Balderdash (n.), a rapidly receding hairline.
11. Testicle (n.), a humorous question on an exam.
12. Rectitude (n.), the formal, dignified bearing adopted by proctologists.
13. Pokemon (n!), a Rastafarian proctologist.
14. Oyster (n.), a person who sprinkles his conversation with Yiddishisms.
15. Frisbeetarianism (n.), The belief that, when you die, your Soul flies up onto the roof and gets stuck there.
16. Circumvent (n.), an opening in the front of boxer shorts worn by Jewish men.



**PLEASE REMEMBER!!!**

**TO RENEW YOUR MEMBERSHIP IN JUNE FOR 2005 - 2006**

We are a very small organisation with a part time administrator working 12 hours a week. 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!

**2005-2006 MEMBERSHIP**

**CATEGORY & AMOUNT (Inc. GST) – JULY 2005 – JUNE 2006**

Ordinary .....	\$55.00
Pensioner/Full Time Student.....	\$20.00
Hospice Palliative Care Volunteers.....	\$20.00
Corporate.....	\$137.50

*PCWA's Executive Committee continues to look for members who are interested in joining the Committee. We need new blood! The demands are reasonable with one monthly meeting and extra activity during Palliative Care Week. PLEASE express your intent on joining the Executive. Contact Clive Deverall on 0417 933554*

