

Access to Palliative Care Medicines in the Australian Community

The Palliative Care Medicines Working Group (PCMWG) progress report and work plan November 2006

1. Introduction

This paper provides background (including an overview of progress to date) on how the Australian Government is progressing access to palliative care medicines in the community as part of the National Palliative Care Program.

1.1 National Palliative Care Program

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 funding of \$55 million over four years (2002-2006) for the *Palliative Care in the Community* Program – national activity to improve the standard of palliative care offered in local communities. *Palliative Care in the Community* funding was renewed in the 2006 Federal Budget for a further four years with funding of \$62.8 million. These funds will support and build on the work of the National Palliative Care Program for a further four years (2006-2010).

The implementation plan for the renewed program will be developed across the following four priority areas:

- Support for patients, families and carers in the community
- Increased access to palliative care medicines in the community
- Education, training and support for the workforce
- Research and quality improvement.

Underpinning the National Palliative Care Program is the National Palliative Care Strategy (**Link to Strategy**) endorsed by the Australian Health Ministers' Advisory Council in October 2000.

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

2. The Palliative Care Medicines Working Group

With a significant proportion of the Australian population requiring palliative care choosing to be cared for and to die at home, access to and quality use of palliative care medicines in the community has been a priority area of the Australian Government's National Palliative Care Program since 2002. To address this priority area, the Department established the Palliative Care Medicines Working Group (PCMWG) to provide clinical and technical support and advice to the Department. The group's terms of reference include improving:

- access to palliative care medicines;

- improving the quality use of palliative care medicines; and
- improving awareness of both the medicines that are available through the PBS and the need for additional research to be done to support the registration of palliative care medicines on the Australian Register of Therapeutic Goods (ARTG).

Membership of the PCMWG is multidisciplinary and includes representatives from the following broad range of stakeholders necessary to support the delivery of high quality effective palliative care across all settings, including representatives from:

- Palliative Care Australia
- Palliative Care Intergovernmental Forum
- Joint Therapeutics Committee for Palliative Care Australia, Australian New Zealand Society for Palliative Medicine and the Clinical Oncological Society of Australia
- Cancer Council Australia
- National Prescribing Service (NPS)
- Australian Pharmaceutical Advisory Council
- Drug and Therapeutics Information Services
- Medicines Australia
- Rural Doctors' Association of Australia
- Community Nursing
- Pharmacy Guild of Australia
- Consumers Health Forum
- Medicare Australia
- Therapeutic Goods Administration (TGA)
- Pharmaceutical Benefits Advisory Committee (PBAC) Secretariat
- Department of Health and Ageing
- Cancer Australia

2.1 Communication Sub-group

In June 2005, a communication sub-group of the PCMWG was established to specifically address issues concerning communication, education, and awareness raising of the medicines listed in the PBS Schedule. The sub-group's role is to provide advice to the PCMWG on strategies to:

- inform and raise awareness of the medicines available to be used in the community to relieve symptoms in palliative care;
- promote quality use of palliative care medicines in the community by educating:
 - the primary health workforce and other health professionals about symptom management in palliative care and the quality use of medicines including raising their awareness around the Therapeutic Guidelines for Palliative Care and the guidelines put out by the Australian Pharmaceutical Advisory Council on medication management in residential aged care settings and the community setting; and
 - families and carers on the quality use of medicines, including what questions to ask, how the use of specific medicines may apply to them and improving their understanding of the benefits, risks and effects.
- promote awareness raising among clinicians and the pharmaceutical industry in the role they can play in generating the evidence to support future listing of palliative care medications through the PBS.

- Raise the awareness amongst GPs, Palliative Care Specialists and the palliative care community about the complexities of getting medicines listed through the PBS and the need to consider current medicines available which can be used to relieve symptoms

3. The Issues and Barriers

3.1 Access to Medicines

There are a number of significant barriers to achieving the listing of all of the medicine used in the hospital setting on the PBS. These barriers include:

- the medicine not being registered by the TGA for supply in Australia for use in any medical condition
- the medicine being registered but not PBS-listed for indications for use in palliative care
- the specific dosage and formulation needs for administration to palliative care patients not being registered by the TGA and
- many of the medicines are low usage medicines or out of patent and therefore there is little incentive for manufacturers to invest money to have the medicine registered by the TGA.

Palliative medicine and its research cultures are evolving fields. Many longstanding prescribing practices are empirical and local, and have not been well-researched or well-documented in the past. Resources for research have been limited, and many of the research questions that need to be addressed are unlikely to attract funding from the pharmaceutical industry. Practical problems of recruitment, consent, and infrastructure for research projects also hamper the development of the evidence base for palliative care prescribing.

The inability of medicines to be listed on the PBS means that some of the medicines for palliative care are not accessible at a subsidised rate in the community and may be unaffordable for some patients. This can result in a reduced ability to adequately manage symptoms or may result in unnecessary admissions to a hospice or acute care hospital for stabilisation and medication management. This situation places an unnecessary burden on the hospital and hospice setting, is disruptive for patients and reduces their option to be cared for in their home.

While some states and territories have put in place ad hoc arrangements to address this important issue, there is no nationally consistent way of ensuring that patients wishing to be cared for in their own home have the same access to medicines as a patient who is cared for in a hospital setting.

3.2 Quality Use of Medicines

The quality use of medicines in palliation is very important within the community setting. Prescribing doctors need to consider the:

- appropriateness of a medicine particularly if it is not currently registered for a palliative care indication on the Australian Register of Therapeutic Goods (ARTG);

- added costs incurred by the patient if the medicine is not listed on the PBS;
- appropriateness of the mode of administration within the community setting;
- availability of the medicine in pharmacies, particularly if the patient is discharged from hospital back to a rural setting; and
- education requirements of patients, families and carers.

The need to educate and support GPs and other primary health care workers in the management and care of palliative care patients in the community is an ongoing issue. GPs may only care for 3-4 palliative care patients per year. There is a need therefore to ensure that GPs have the support and resources readily available to them to confidently manage patients when they present. Their involvement in discharge planning is essential to ensure quality use of medicines in the community.

In addition there is a need to encourage the gathering of clinical evidence to support the listing of palliative care medicines on the ARTG. This will require the support and education of palliative care specialists and other prescribing doctors.

3.3 Awareness

Since the inclusion of the Palliative Care Section in the Schedule of Pharmaceutical Benefits in February 2004, utilisation rates of the various medicine listed have varied significantly.

The low usage of some of the drugs listed in this section could possibly be the result of a number of factors including:

- poor advertising of the Palliative Care Section within the medical sector;
- doctors unaware of the medicines available in the Palliative Care Section of the Schedule as they tend to use on-line prescribing services that do not identify palliative care medicines;
- as some medicines can be accessed over the counter relatively cheaply, there is little incentive for a patient to ask the GP for a script for these medicines;
- traditional methods of accessing these medicines (that is through the hospital system) is continuing; or
- perceived difficulties by medical practitioners in gaining authority from Medicare Australia.

Other awareness raising issues that need to be considered include:

- the need to raise awareness within the pharmaceutical industry of medicine usage in palliative care; and
- the need to ensure that palliative care researchers/specialists are involved in research to support the gathering of evidence to facilitate the registration of palliative care medicines on the ARTG.

4. Work to date

4.1 Access to Medicines

4.1.1 Palliative Care Section in the PBS Schedule

In February 2004 a dedicated Palliative Care Section was established within the Schedule of Pharmaceutical Benefits. For the purpose of prescribing under the Palliative Care Section of the PBS Schedule, a patient receiving palliative care is defined as: *A patient with an active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life.*

All palliative care listings are “Authority Required”. All prescribers can request an initial authority to provide a maximum of 4 months therapy for palliative care patients. Where a subsequent authority is requested for continuing treatment, the provision of repeats is subject to confirmation by the prescriber that a palliative care physician or palliative care service has been consulted regarding the care of the patient. This could mean a phone call to a palliative care physician or service. The patient does not need to be seen by the service.

Attachment A provides a full list of the medicines currently listed in the palliative care Schedule. To access the full list of medicines on the PBS go to Schedule of Pharmaceutical Benefits at: www.pbs.gov.au

4.1.2 Palliative Care Clinical Studies Collaborative

In June 2006 the Australian Government provided seed funding to support the development of the Palliative Care Clinical Studies Collaborative. The Palliative Care Clinical Studies Collaborative or PaCCSC is a collaborative network of researchers from around Australia who have joined forces to facilitate the generation of the scientific evidence to support the registration of medicines on the Pharmaceutical Benefits Scheme (PBS).

4.2 Quality Use of Medicines

Under the National Palliative Care Program a number of projects, resources and research studies have been funded that will result in the improved quality use of palliative care medicines in the community. A program overview can be found at www.health.gov.au/palliativecare

Specific projects of interest that have been funded include:

- The Evidence Based / Knowledge Network Project which has resulted in the development of the CareSearch website. www.caresearch.com.au. This website will eventually evolve to become the Australian Palliative Care Knowledge Network that will provide a one stop shop of information and resources for those affected by or involved with the provision of palliative care services.
- The Education, Training and Support Needs of General Practitioners which has resulted in the development of the Clinical Diploma of Palliative Medicine.
- The National Pharmaceutical Opioid Medication Management in Palliative Care Project which resulted in an on-line Opioid Education training package for GPs.
- Guidelines for a Palliative Approach in Residential Aged Care. More information on this work is available from the Palliative Care Australia website <http://www.pallcare.org.au/>

- Development of guidelines to support pain management in aged care homes funded. This resulted in the resource *Pain in Residential Aged Care Facilities* published in August 2005. This resource can be access from the Australian Pain Society website: <http://www.apsoc.org.au/>
- The Palliative Care Trial: A study of the use of Enhanced Primary Care Items and Educational Intervention (specific focus on pain management)
- The Palliative Care Research Program. This program funded a number of research studies that will have an impact on the quality use of medicines in palliative care. A full list of the research funded under this program can be found as an attachment to the Program overview. A new research program has commenced as part of the renewed Palliative Care in the Community 2006 Federal Budget measure.

4.3 Awareness Raising Activities

The Palliative Care Medicines Working Group has undertaken a number of activities over the past four years that have been designed to raise awareness of the:

- medicines available within the Pharmaceutical Benefits Scheme that can support symptom management in palliative care Patients;
- process for listing medicines through the Pharmaceutical Benefits Scheme; and
- need for research to support the further listing of medicines for palliation on the Pharmaceutical Benefits Scheme.

To support these activities the Palliative Care Medicines Working Group has established a national communication network of pharmacists, palliative care specialists and other health professionals to undertake awareness raising activities at the local level.

A number of fact sheets and other resources to support communication network members have been developed. These include:

- **Why is access to medicines for palliative care an issue?** (Fact sheet) (279KB PDF )
- **Palliative Care Medicines and the Pharmaceutical Benefits Scheme (PBS)** (Poster) (539KB PDF )
- **Improving community access to palliative care medicines** (Fact sheet) (217KB PDF )

5 Future work

5.1 Access to medicines

The Australian Government has provided seed funding for the Palliative Care Clinical Studies Collaborative to support the gathering of evidence required to list further medicines on the PBS.

5.2 Quality use of medicines

- Scope the possibility of engaging the sector in supporting educational activities using academic detailing principles that would encourage the uptake of the medicines currently on the PBS; and
- Considering the educational needs of pharmacists.

5.3 Awareness raising

- Continue to support the communication network to include health professionals in areas not currently covered;
- Scope the needs of patients, families and carers in raising awareness of and quality use of palliative care medicines; and
- Scope the awareness needs of GPs and other health professionals once the Yellow PBS schedule is no longer printed.

ATTACHMENT A

SCHEDULE OF PHARMACEUTICAL BENEFITS - PALLIATIVE CARE SECTION

February 2004	<ul style="list-style-type: none"> ➤ Carmellose Sodium (four items) * ➤ Hyoscine Butylbromide (two items)* ➤ Promethazine Hydrochloride (six items)* ➤ Bisacodyl (six items) ➤ Ducusate Sodium with Bisacodyl (two items) ➤ Sterelia with Frangula Bark (four items) ➤ Bisacodyl enema (two items) ➤ Sorbitol with Sodium Citrate and Sodium Lauryl Sulfoacetate enema (two items) ➤ Glycerol (six items) ➤ Paracetamol suppositories (two items)* ➤ Clonazepam (six items)*
April 2005	<ul style="list-style-type: none"> ➤ Paracetamol modified release tablets (two items)*
December 2005	<ul style="list-style-type: none"> ➤ Diclofenac Sodium (six items) ➤ Indomethacin (four items) ➤ Sulindac (four items) ➤ Imuprofen (four items) ➤ Naproxen (eight items) ➤ Naproxen Sodium (two items) ➤ Diazepam (four items) ➤ Oxazepam (four items) ➤ Nitrazepam (two items) ➤ Temazepam (two items)
August 2006	<ul style="list-style-type: none"> ➤ Lactulose (two items) ➤ Macrogol 3350 (two items) ➤ Morphine Sulphate (six items) ➤ Benzydamine Hydrochloride (two items) ➤ Naproxen oral suspension (two item)

* Represents those medications that are not dual listed