PalliativeCare AUSTRALIA

His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd), Governor-General of the Commonwealth of Australia, Patron

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Senator Rachel Siewert
Chair
Community Affairs References Committee
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Senator Siewert

Submission to inquiry on the availability of new, innovative and specialist cancer drugs in Australia

Thank you for the opportunity to make a submission to the inquiry on the availability of new, innovative and specialist cancer drugs in Australia.

Palliative Care Australia (PCA) is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together PCA members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.

In examining the issue of the availability of cancer drugs to patients, the full range of medications and treatments that would benefit people living with cancer must be considered, including those which address quality of life issues. This includes palliative care medications which, along with cancer specific medications, impact on the quality of care available to cancer patients, including where drugs are not listed on the Pharmaceutical Benefits Scheme (PBS).

Medications commonly used in palliative care, glycopyrrolate and midazolam, are not listed on the PBS, creating difficulties and additional cost for individuals wanting to receive palliative care at home from a family member or carer. These drugs are very cost effective, compared to other medications that this Committee will be considering.

An issue worthy of consideration by the Committee is the increase in the number of patients self-funding expensive chemotherapy medications that are not covered on the PBS. There are a number of patient access schemes where people make substantial co-payments for medications that have been declined for PBS status. This can place substantial pressure on patients and families to purchase these drugs, which in some cases have limited efficacy, particularly where they may not be able to afford them. This is not to question the PBS listing process or to suggest they should be listed, but to note

for consideration what treatments are effective and that there should be some oversight of these processes, particularly where treatments lead to substantial out-of-pocket costs.

A further issue not related to PBS listing but associated with timing and access for patients, is access to medications in community care that may be required for urgent symptom control, such as pain crises or restlessness (e.g. newer synthetic injectable opioids such as hydromorphone and midazolam). Community pharmacies may not have these in usual stock and it can take 1-2 days for stock to be ordered and received. This means that hospital pharmacies often need to prescribe these mediations in an urgent situation, even where the patient has not attended that hospital or may not have been a patient there for some time.

Commonly in community practice, doctors and nurses in palliative care will contact a number of pharmacies to check stocks, often then needing patients, family or carers to travel long distances to collect medications. It is recognised that pharmacies cannot stock all medications, however, a possible solution may be to establish designated pharmacies in defined areas that have an incentive to stock medications for emergency use.

While the focus of listing new cancer drugs and their affordability is on extending the life of a person diagnosed with cancer, the quality of life of the person is equally as important, and any medications that can assist the person and their family or carer/s to achieve this, should be a part of the overall consideration. This includes older and commonly used drugs that are used for comfort, including in the late and terminal stages of malignancy.

Palliative care improves the quality of life of patients by providing relief from pain and other distressing symptoms, and offers a support system to help patients live as actively as possible. It is also applicable early in the course of an illness in conjunction with other therapies, such as chemotherapy, radiation and other cancer medications.

The Australian Institute of Health and Welfare *Palliative Care Services in Australia 2014*, as in previous years, showed that the largest number of people receiving palliative care had a cancer diagnosis. Therefore it is vital to consider the full spectrum of care that a person living with cancer receives, taking into account quality of life and affordability issues and the person's wishes in how and where they want to receive care.

Palliative care is an integral part of the spectrum of care for a person living with cancer and the affordability and availability of palliative care medications should be given equal consideration.

Yours sincerely

Liz Callaghan
Chief Executive Office