9 April 2010

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Secretary

Re: Inquiry into Consumer Access to Pharmaceutical Benefits

We welcome the opportunity to respond to this inquiry. Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socio-economic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, mental health, community care and palliative care systems. Without family carers these systems could collapse, with serious consequences. Family carers have been identified as the invisible health workforce because of the level of care they provide. This can include taking responsibility for ensuring compliance with often complex medication regimes. Therefore, no changes to pharmaceutical benefits should be implemented without a full understanding of how medication is often managed in the home.

Carers Australia has several concerns regarding the potential impact of therapeutic groups on the lives of family carers. We are concerned that the introduction of new therapeutic groups has the potential to:

- force patients to switch to medicines less suited to their particular circumstances
- influence the prescribing practices of doctors through budgetary pressure rather than the clinical needs of the patient
- raise risks for patients by increasing the possibility of non-compliance through disruption to regular treatment patterns, which can have negative outcomes for carers
- increase costs to patients if a company making the medication makes decision to introduce a brand premium
- increase costs to the healthcare system.

Important concerns for family carers include possible interactions between existing medication regimes and any new medications, non-compliance by patients and increases to costs of medication.

In the case of certain medications, for example for the treatment of severe mental illness, changes to medication regimes have the potential to have negative outcomes for the safety of family carers, particularly when carers are not informed of these changes.

Many carers face financial hardship through reduced capacity to engage in employment and the high costs related to care provision. Any increase in the cost of medication could be as serious as choosing between food on the table, looking after their own health and filling prescriptions for the person for whom they are caring. It is often the case that carers simply have no room to move financially to meet the increased cost of medications.

Feedback from carers often highlights the financial strain experienced by caring families:

> *"My own health is deteriorating. I suffer severe back pains, my teeth are falling apart, my migraines are getting more frequent, sciatica is worsening, arthritis is beginning to surface and the list goes on. I am unable to tend to these problems because of the enormous cost"*
> — Carer of adult daughter

> *"I have to work to pay for the house and living expenses...If I was to loose my job I would loose my house and my car. There is not enough money for medical care… Most of the money we receive goes on everyday expenses. We do not have credit cards because that wastes money (interest and fees). What do we do when we have no resources to pay for medical care that we need as a family. I have a shoulder injury and am in constant pain myself. I can't afford ongoing care for myself."* — Carer of husband

To address these concerns, the introduction of any changes to pharmaceutical benefits should be accompanied by guidelines, protocols and information that will assist prescribing health professionals to adopt a 'whole of family' approach that is inclusive of the needs of family carers. An effective example of such guidelines is the draft Clinical Guidelines for Stroke Management 2010, produced by the National Stroke Foundation[i] which includes carer support as a principle of good practice for health professionals.

Another consideration in this process should be the principles in the recently-tabled Carer Recognition legislation. These principles clearly state that carers "should be treated with dignity and respect" and "considered as partners with other care providers in the provision of care."[ii] The inclusion of these principles in any policy related to the consumer access to pharmaceutical benefits would reflect the legislative supports that will be introduced for family carers under the Carer Recognition Bill 2010.

I would like to thank the committee for its consideration and would welcome the opportunity to provide further input into this inquiry.

Yours sincerely

JOAN HUGHES
Chief Executive Officer

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[i] Available at National Stroke Foundation website
http://www.strokefoundation.com.au/clinical-guidelines

[ii] Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) (2010) Carer Reconition Bill 2010 accessed 9 April 2010
http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:"legislation/bills/r4342_first/0001";rec=0