

24 May 2007

Mr. Elton Humphery
Committee Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Humphrey

Inquiry into the operation and effectiveness of Patient Assisted Travel Schemes

It is with great pleasure that I enclose our submission to the Senate Inquiry.

We would be delighted to address the committee to talk further on this matter should the Committee hold public hearings at a later date.

John Stubbs, Executive Officer will be our representative at the public hearing.

Yours faithfully

John Stubbs
Executive Officer

**SUBMISSION FROM CANCER VOICES AUSTRALIA TO THE SENATE INQUIRY
INTO THE OPERATION AND EFFECTIVENESS OF PATIENT ASSISTED
TRAVEL SCHEMES (PATS)**

MAY 2007

Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes – Australian Senate

Introduction

Cancer Voices Australia (CVA) is a national cancer consumer organisation representing Australians affected by cancer. It aims to ensure the voices of people affected by cancer are heard at a national level.

Objectives

- To promote the fundamental rights of Australians affected by cancer
- To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation
- To promote the value and benefits of consumer participation in the development of national cancer policy and programs
- To provide a forum for member organisations to network and contribute to national activities

Cancer Voices Australia seeks to ensure that all cancer patients in this country receive access to national minimum standards for PATS regardless of their state or territory. Our response will address this.

And in the words of Dr. Martin Luther King

"Of all forms of inequity, injustice and inequity in health is the most inhumane,"

Statement

In Australia each year, more than 98,000 new cases of cancer are diagnosed. More than half of the cases will be successfully treated. There are over 280,000 Australians either living with or still being treated for cancer. (AIHW)

Many of these Australians live in the outer metropolitan, rural and remote regions where access to medical services is limited. As a result of this and their cancer diagnosis which requires expensive and continued treatment, a large number of cancer patients must travel to the treating hospitals situated in their capital city or a large regional centre.

A cancer diagnosis can be a life changing experience. People face both physical and psychological challenges throughout their cancer journey. The cost of travel to their treatment centre, the loss of their support and family networks and often loss of income can add considerably to their cancer burden.

Cancer Patients in each state and territory have access to a state funded travel and transport scheme – but there are severe restrictions that can apply. Each state and territory appears to be different, identifying their schemes by different names, and having different criteria for eligibility.

CVA welcomes this inquiry which will highlight the issues faced by cancer patients, their carers and family in each state and the effect on their cancer outcomes.

The Scheme(s)

PATS is not only relevant to cancer patients – it affects a large number of patients with chronic diseases. We recognise that the transport and travel system is open to all patients – but our submission deals with cancer patients and issues pertinent to them.

In Australia in recent years there have been many inquiries and reports concerning cancer and its treatment and delivery of services.

The recent Senate Community Affairs Reference Committee *The Cancer Journey – Informing Choice* Report (June 2005 ISBN 0 642 71509 2)_ Recommendation 20 stated that the States and Territories adopt and implement a consistent approach to the benefits for travel and accommodation to ensure that benefits are standardised across Australia. In addition they recommended that these benefits should be indexed or reviewed annually for increases in travel and accommodation costs. The Senate Committee Report is in fact just the latest in a series of reports into this issue.

The difference between the current schemes are highlighted at Annex A

CVA has canvassed its constituency and nearly all felt that there should be a national minimum standard for PATS. There are some differences in certain States that are positive, for example in Tasmania the cut off point for eligibility is 75kms. QLD, with its 50kms, seems ideal as many of the outer metropolitan areas are that far from the treatment centres. This latter point is most appropriate for both Sydney and Melbourne as the distances to the treatment centre can exceed 50 kms.

Given that many patients need carers to accompany them, the current demand on available accommodation (some hospitals have accommodation) is great and families at times have to be accommodated in commercial accommodation. However, the rate of reimbursement for transport and accommodation costs never keeps pace with costs of travel or hotel/motel tariffs

CVA canvassed patient responses to the current system and they are attached at Annex B.

Addressing the TOR

The operation and effectiveness of Patient Assisted Travel Schemes including:

- a) **the need for greater national consistency and uniformity of Patient Assisted Travel Schemes across jurisdictions, especially the procedures used to determine eligibility for travel schemes covering patients, their carers, escorts and families; the level and forms of assistance provided; and reciprocal arrangements for inter-state patients and their carers;**

CVA Response

See Recommendation 1 below, Annex A and patients' responses at Annex B.

- b) the need for national minimum standards to improve flexibility for rural patients to access specialist health services throughout Australia;**

CVA Response

- c) the extent to which local and cross-border issues are compromising the effectiveness of existing Patient Assisted Travel Schemes in Australia, in terms of patient and health system outcomes;**

CVA Response

The Australian Government to provide a 'gap' service to ensure that there is no compromise in terms of patient outcomes

- d) the current level of utilisation of schemes and identification of mechanisms to ensure that schemes are effectively marketed to all eligible patients and monitored to inform continuous improvement;**

CVA Response

See Recommendation 2 below

Both levels of Government should raise the public awareness of the schemes and provide education and training to GP's to provide the information to patients, their families and carers at time of diagnosis.

- e) variations in patient outcomes between metropolitan and rural, regional and remote patients and the extent to which improved travel and accommodation support would reduce these inequalities;**

CVA Response

The big issues are subject to the assessment of the patient, and the mode of travel, (highlighted by WA, SA, NT and QLD with their large distances) and whether a carer should be funded at all. It should be the decision of the clinician (or even the patient) to decide whether or not a carer travels with them.

The patient is often referred to and seen by the nearest 'local' specialist who may not have a background in the treatment of that particular cancer. Modern, multi-disciplinary treatment of cancer requires specialists to adhere to national treatment guidelines and a volume throughput in treating a certain type of cancer. Automatic referral to a 'visiting specialist' or the 'nearest centre' may be beneficial to the PATS budget but may well prejudice a patient's prognosis.

From patients:

The process can be so stressful and difficult that for patients and their carers, that many people decide not to have treatment at all. (WA, SA, NSW)

See Recommendation 6

- f) the benefit to patients in having access to a specialist who has the support of a multidisciplinary team and the option to seek a second opinion;**

CVA Response

Multidisciplinary care (MDC) has been shown to improve care and outcomes for patients with cancer. For a number of years consumers have advocated for this treatment protocol to be incorporated into national and state/territory clinical practice guidelines, frameworks and plans across Australia. It is now being achieved.

The local PATS budgets are regarded as belonging to the states or PATS offices and not the patients and funding access is difficult, thereby affecting possible patient outcomes.

See Recommendation 6

- g) the relationship between initiatives in e Health and Patient Assisted Travel Schemes;**

CVA Response

The provision of e Health must be linked to the practice of Multi Disciplinary Care for cancer patients. A fully operation system that also addresses the cross-border issues (should they apply) would be of great benefit to the patient. The introduction of a linked e Health system would enable to patient to stay near to their home, visit the local Dr and be given the same information and treatment pathway and not travel to the city or large treatment centre can only be a positive situation for the patient. PATS will not apply – a positive for many rural and remote patients,

- h) the feasibility and desirability of extending patient assisted travel schemes to all treatments listed on the Medicare Benefits Schedule – Enhanced Primary Care items such as allied health and dental treatment and fitting of artificial limbs; and**

CVA Response

No comment

- i) the role of charity and non-profit organisations in the provision of travel and accommodation assistance to patients.**

CVA Response

Charities and NGOs like the Leukaemia Foundation Australia, Ronald McDonald house, Starlight Foundation, Red Kite and the state Cancer Councils, to name a few, already provide not only accommodation but resources that greatly assist cancer patients and their families who travel to the city for their treatment. These organisations, which in turn save the PATS system considerable funds, are well placed to increase their role in this capacity. They have the systems, they have the personnel and they have the trust and respect of cancer patients. The Australian Government through one off capital grants for accommodation close to treatment centres could 'fill the void'.

The centres would be managed and run by the charities.

The latest information available is the recently published Cost of Cancer Report by the Cancer Council NSW and Access Economics. The figures (for NSW only) are \$2.5M spent by charities on providing accommodation to people with cancer - \$59.00pp with active cancer. (page 99). A conservative estimate across Australia is double that amount.

See Recommendation 7

Other Issues

Clinical Trials

Government Policy seeks to have 10% of eligible patients enrolled in clinical trials. However, only some of the states' PATS schemes allow reimbursement to the patient for travel to the trials centre, again highlighting the differences.

Recommendations

- 1. All cancer patients in this country receive access to national minimum standards for PATS regardless of their state or territory. The per km amounts should be those amounts allowed by the Australian Taxation Office.**
- 2. Introduce a national awareness and training campaign for all clinicians, health care and PATS workers and establish bone fide links with all agencies to ensure that cancer patients and their families have access to all relevant information regarding financial assistance programs**
- 3. A means tested allowance to be paid to cancer patients at the time of diagnosis – similar to the Carers' Allowance. The allowance would lapse when remission of the patient's cancer occurred,**
- 4. Fuel rebate cards be issued to patients and carers to be used specifically for travel to and from their treatment centre**
- 5. PATS offices to negotiate rates with accommodation agencies near treatment centres**

6. **Multi-Disciplinary Treatment (MDT) for cancer is considered the optimal treatment pathway. PATS must develop a policy in Australia that will facilitate each patient's access to MDT.**
7. **The Government provide capital grants to current NGOs and charity providers of accommodation to expand their services. Current accommodation services provided by these authorities are first class and save the PATS program money.**

References

The Cost of Cancer in NSW - Cancer Council NSW and Access Economics April 2007

The Cancer Journey – Informing Choice Report (June 2005 ISBN 0 642 71509 2_

National Service Improvement Framework for Cancer. National Health Priority Action Council January 2004

National Aged Care Alliance Position paper

Radiation Oncology Jurisdictional Implementation Group Final Report, Commonwealth of Australia 2003 (see attachment 4.1 Physical Patient Access Working Group – Final Report)

Optimising Cancer Care in Australia. A consultative report by the Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative, 2003

Clinical practice guidelines for the psychosocial care of adults with cancer, National Breast Cancer Centre and the National Cancer Control Initiative, 2003

Localised prostate cancer: a guide for men and their families. Australian Prostate Cancer Collaboration 2003

Living with Cancer Conference, Report of Proceedings. Canberra 2002

Cancer in the Bush, Optimising Clinical Services, Report and Recommendations from a meeting held at the National Convention Centre, Canberra 2001

Clinical practice guidelines: management of early breast cancer. iSource National Breast Cancer Centre 2001

Annex B

CVA has stressed throughout its submission the impact that cancer has on the patient and their families. Below outlines many of the issues associated with the current PATS scheme(s) that are identified by cancer patients.

The Patient Stories

- The process can be so stressful and difficult that for patients and their carers, that many people decide not to have treatment at all. (WA, SA, NSW)
- For haematology patients whose treatment often extends for 6 months or more the scheme normally won't fund past 6 months. (All states)
- There is no meaningful increase in the rate of reimbursement - and certainly not in line with inflation or the recent jump in fuel prices. (all states)
- Many treatment centres don't have any dedicated accommodation - so commercial facilities have to be used. The problem is exacerbated with as most treatment centres close to the centre of a city or city fringe where accommodation is expensive. (All states)
- Many people live just under the designated km limit, e.g.: limit is 100 kms and a person living 95kms from the treatment centre has no flexibility at all - those people have to absorb the complete cost of travel. Victoria does have a sensible gap protection (75 – 99kmns) (WA, NSW, SA)
- One patient lives 10kms from the centre of town, but the GPO address is 97kms so there is no eligibility under the current strict guidelines. (WA)
- The scheme requires up front payment - many cannot afford this.
- Social workers spend many hours advocating with PATS personnel, accommodation providers, and chasing Drs to fill forms, etc. (NSW, SA, WA)
- In QLD, - individual hospitals administer the scheme.
- Accommodation near the treatment centres costs a minimum of \$90.00. (All States)
- There is no consistency and many people fall through the gaps. (All states)
- Many people, including locum doctors, still don't know about the scheme. (All states)
- Many people are living on one income or pension, so finances already extremely burdened. (All states)
- Reports of PATS staff not being helpful or inconsistent (NSW, WA, SA, Vic)
- Reimbursement can take up to 3 months or more - this is really difficult for people already financially burdened. (All states – but QLD best)
- The time for reimbursement can often be speeded up by the established relationship that the Social worker has with the PATS officer (NSW, SA, WA)
- The cost of parking at major hospitals, the limited parking available, and the complexity of getting into car parks is cited frequently by rural patients as a deterrent to continuing treatment. (All states)
- Assessment is based on medical grounds with little or no consideration being given to psychosocial need. The evidence supports the view of some health care workers that the need for an escort should be at the discretion of the patient and not the PATS officer. (All states)
- Charities fill the gaps. (All states)