

POSITION STATEMENT

STATE AND TERRITORY TRAVEL AND ACCOMMODATION SUBSIDY SCHEMES

Summary statement

People with cancer living in rural and remote areas are more likely to experience greater problems and concerns associated with travel for treatment and follow up care than their peers who reside in urban or regional cities.¹ Across Australia, these problems are compounded by access and equity issues associated with travel and accommodation subsidy schemes.^{2,3,4} People will have ways of coping with the inconvenience and practical hardship that travelling for treatment causes. The role then of government and non-government providers alike is to build on these strengths, and provide effective emotional, informational and practical assistance so that adjustment, functioning and quality of life can be improved.¹

Recommendations:

The Cancer Council Australia supports the immediate establishment of a Commonwealth-funded Task Force to address the identified problems associated with travel and accommodation subsidy schemes for people from rural and remote areas. The focus will be to:

1. Establish the feasibility of a cooperative approach to standardised eligibility criteria between the Commonwealth and states and territories.
2. Specifically consider the needs of individuals at increased risk of psychosocial problems and populations experiencing disproportionate difficulties with access to schemes, such as Australian aboriginals.
3. Assess mechanisms to improve the current financial assistance provided for a person with cancer and their carer/ escort.
4. Consider assistance for accessing the treatment and treating physician of a person's choice and accessing a second opinion on treatment options.
5. Develop an awareness campaign for health care workers and people from rural and remote areas travelling for cancer treatment. This would include the availability of the schemes and eligibility criteria and how to access these and other financial assistance programs (for example with social work assistance)^{2,3,4}
6. Develop recommendations in response to 1–5.

The problem

Background

The impact of travel on peoples' experiences of cancer treatment have consistently been described as inconvenient and a practical hardship.⁵ In Australia, assistance has been available since 1978 to help subsidise the costs of travel and accommodation of people living in rural and remote areas who require specialist medical treatment not available locally. Initially the scheme was administered by the Commonwealth but responsibility was transferred to the states and territories in 1987. On the whole, financial assistance for travel and accommodation is valuable. However, serious concerns associated with access and equity have arisen since devolution to the states and territories and it has been identified that schemes are not working as well as they could for people affected by cancer.^{2,3,4}

Australia's population is highly dispersed and it is estimated that approximately 30% of all people with cancer live outside a major population centre.⁵ At the same time, cancer treatment is complex and can involve different modes of delivery, multiple specialists and the need for highly specialised equipment. These two factors combined mean that it is unlikely that people treated in rural and remote areas will ever be able to access all the services they require locally and therefore there will be an ongoing need for travel for some components of cancer care.⁵

Lack of information

People with cancer report they are often given insufficient information about financial assistance schemes. A study of eighty rural women travelling to the city for breast cancer treatment found that only 39% of them received financial assistance and 19% of these had trouble claiming money for which they were eligible.⁶ Similarly, the *Draft National Service Improvement Framework for Cancer*⁵ refers to a study of 192 people with haematological malignancies who travelled for treatment, with one quarter of those surveyed identifying that they had never heard of the local assistance scheme. Scheme awareness was also identified as a major impediment to access in the *Radiation Oncology Jurisdictional Implementation Group Final Report*^{1,2}.

Inequity

The *Living with Cancer Conference*² identified as a priority the need to address inequities in the application of travel and accommodation schemes across state and territory jurisdictions. *Optimising Cancer Care in Australia*⁴ goes one step further, stating that "There is variation between and within jurisdictions, in the rules that apply and the manner in which they are applied." Further significant difficulties occur around the issue of a carer/ escort to accompany a person travelling for treatment. Assessment is often based on medical grounds rather than consideration being given to psychosocial need. The evidence associated with the distress caused by being away from home, family and friends for

extended periods of time supports the view of some health care workers that the need for an escort should be at the discretion of the person undergoing treatment. This is an important issue for all people; however, for groups such as Aboriginal and Torres Strait Islander peoples or those from culturally and linguistically diverse backgrounds, the disadvantage is compounded.⁴

Financial issues

Out-of-pocket-expenses associated with travel and accommodation can add significantly to the overall expenses of people who need to travel greater distances for treatment. Often two households are needing to be maintained with all of the associated costs. The estimated expenses highlighted in the National Breast Cancer Centre report *Out-of-pocket-expenses incurred by women for diagnosis and treatment of breast cancer in Australia*⁷ provide evidence of the extent of outlay incurred even when a government-funded scheme is taken into account. Financial difficulties associated with the need to travel are further compounded by circumstances such as a loss of income due to treatment or for people who are of limited means prior to diagnosis. Up-front payments required by some jurisdictions also have significant impact.

Special considerations

Consideration also needs to be given to the needs of people living just within the limit of assistance. People with cancer who reside within 90kms of a treatment centre are likely to have the same levels of need as a person living in a rural and remote area (as designated by a 100km zone). The question of access to a second opinion, and choice of specialist and treatment centre also warrant consideration, particularly where clinical and consumer guidelines provide evidence that these strategies represent best practice.^{8,9,10}

The solution

The Cancer Council Australia's goal is to lead the development and promotion of national cancer control policy in Australia, in order to prevent cancer and reduce the illness, disability and death caused by cancer. It does this by working together with its eight member state and territory cancer organisations. Among other cancer-control activity, The Cancer Council Australia advocates on behalf of people affected by cancer to ensure that issues related to cancer care get the attention, legislative action and funding they deserve.¹¹

The problems outlined above have emerged time and time again from numerous journal articles, reports and papers. The *Living with Cancer*², *Cancer in the Bush*³ and *Optimising Cancer Care*⁴ reports record the collective views of consumers, practitioners, researchers and organisations involved in cancer care from across Australia, and they are unanimous in their call for action.

The Cancer Council Australia endorses these comments and calls for the immediate establishment of a Task Force to address the identified problems

associated with travel and accommodation subsidy schemes for people from rural and remote areas. Such a group should be funded through the Commonwealth, chaired by The Cancer Council Australia and have membership of people with practical and professional experience and expertise in the areas of rural and remote travel and accommodation schemes, policy development, problem-solving and cancer care. The scope of the Task Force will be to:

1. Establish the feasibility of a cooperative approach to standardised eligibility criteria between the Commonwealth and states and territories.
2. Specifically consider the needs of individuals at increased risk of psychosocial problems and populations experiencing disproportionate difficulties with access to schemes, such as Australian aboriginals.
3. Assess mechanisms to improve the current financial assistance provided for a person with cancer and their carer/ escort.
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6. Develop recommendations in response to 1–5.

Further information/reading

Optimising Cancer Care in Australia, National Cancer Control Initiative website www.ncci.org.au to view report or download directly from www.ncci.org.au/pdf/Optim_Cancer_Care.pdf

Out-of-pocket expenses incurred by women for the diagnosis and treatment of breast cancer in Australia, National Breast Cancer website www.nbcc.org.au to view or download directly from www.nbcc.org.au/bestpractice/resources/OPE_expensesofdiagandtreatment.pdf

The Cancer Council Australia website www.cancer.org.au will provide access to all state and territory cancer organisations' websites.

Enquiries about Cancer in the Bush, Optimising Clinical Services Report and Recommendations and Living with Cancer Report of Proceedings to The Cancer Council Australia.

More information about the National Service Improvement Frameworks at the National Health Priority Action Council website at www.nhpac.gov.au/

Fitch Margaret I et al 2003, 'Travelling for radiation cancer treatment: patient perspectives', *Psycho-Oncology*, Vol 12:664-674

McGrath P 1999, 'Experience of relocation for specialist treatment for haematological malignancies', *Cancer Strategy*, Vol 1:157-163

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References

1. *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre and the National Cancer Control Initiative, 2003
2. *Living with Cancer Conference*, Report of Proceedings. Canberra 2002
3. *Cancer in the Bush, Optimising Clinical Services*, Report and Recommendations from a meeting held at the National Convention Centre, Canberra 2001
4. *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
5. *DRAFT National Service Improvement Framework for Cancer*. National Health Priority Action Council January 2004
6. Davis C, Girgis, Williams P, Beeney L. *Needs assessment of rural and remote women travelling to the city for breast cancer treatment*. Australian and New Zealand Journal of Public Health 1998 Vol 22:525-7
7. Butler James RG and Howarth Ann L. *Out-of-pocket expenses incurred by women for diagnosis and treatment of breast cancer in Australia*. NHMRC National Breast Cancer Centre 1999
8. *Clinical practice guidelines: management of early breast cancer*. iSource National Breast Cancer Centre 2001
9. *Guidelines for the prevention, early detection and management of colorectal cancer (CRC)*. National Health and Medical Research Council 1999
10. *Localised prostate cancer: a guide for men and their families*. Australian Prostate Cancer Collaboration 2003
11. The Cancer Council Australia website *About us* www.cancer.org.au
12. *Radiation Oncology Jurisdictional Implementation Group Final Report*, Commonwealth of Australia 2003 (see attachment 4.1 Physical Patient Access Working Group – Final Report) For a copy of this report visit the Australian Department of Health and Ageing website at www.health.gov.au/roi/index.htm