

Summary of recommendations

1. Collaborative approach to accommodation planning state-wide:

- Establish an accommodation task force.
- Develop a range of agreed models for accommodation provision.
- Ensure accommodation facilities are linked with new treatment centres.
- Advocate for consideration of needs of rural patients in treatment process.

2. Coordination of accommodation information and arrangements for each patient:

- Establish a central information point/service.
- Develop a dissemination and publicity strategy to promote the central information service.
- Foster collaboration between accommodation providers.
- Improve and streamline local processes for determining needs and arranging accommodation.
- Facilitate IPTAAS processes.

3. Address issues of additional financial burden:

- Improve access to IPTAAS financial subsidies for accommodation and transport.
- Reduce financial risks to patients, such as loss of home or employment.

4. Improve transport access:

- Establish collaborative patient transport group.

5. Support for rural patients and families:

- Establish hospital-based support for rural patients.

6. Address Aboriginal community access to treatment:

- Establish a state-wide multi-sector working group.

Recommendations in full are available in the project report at www.cancercouncil.com.au

Achieving equal access to treatment is a central goal of both federal and state health strategies. Equal access will only be achieved through addressing the allied challenges of transport and accommodation. The recommendations of this report provide a blueprint for work to improve accommodation services for people affected by cancer in NSW.

Acknowledgements

We would like to thank all the cancer patients, carers, health professionals and accommodation providers who contributed to this work. We are also very grateful to the Social Workers Oncology Group and the Cancer Institute NSW Psycho-oncology and Cancer Nurse Coordinator Forums for their input.

Cancer Council South Australia and the Auckland Cancer Society were very generous with their time and we appreciate the opportunity to draw on their experience. We also thank NSW Area Health Cancer Services and planning executives for their support of the project.

The design of the review was influenced and improved by the comments of an initial Inception Group, and its findings tested, challenged and enhanced by participants in a Pre-Release Workshop. We would like to thank all those who took part for their insight, enthusiasm and participation in the project.

Project Steering Group:
Cancer Council NSW
CanAssist

Completed by:
Cancer Information
and Support Services
Cancer Council NSW
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Hospital-Allied Accommodation, Equity and Access to Health Services

Accommodating Change



Blue Gum Lodge, Greenwich



Queen Mary Building, Camperdown
Closed 2003



Vera Adderley Building, Randwick
Closed 2009



Lilier Lodge, Wagga
Opened 2004

Why accommodation is vital

The complexity and duration of modern cancer treatments plus the geographic spread of treatment centres around NSW makes it necessary for many people to travel and stay away from home to access treatment.

Radiotherapy treatment, for example, often requires daily out-patient attendance over six weeks. Access to specialist facilities is also required for cancer diagnosis, surgery, chemotherapy and follow-up. People living in rural and remote areas face additional financial and psychological distress whenever they need to travel and stay away from home just to attend treatment.

Often the only option for patients and carers is to stay nearby to the hospital for the duration of their treatment. In some cases, people choose the treatment they will have based on the proximity to home, or even worse, refuse treatment.

Review aim

Accommodating Change examined four main questions regarding hospital allied accommodation in NSW:

1. What is the scope and adequacy of current accommodation provision?
2. How does accommodation and associated support impact on the patient cancer journey?
3. How is accommodation currently funded and what are the options for creating models of accommodation that are financially sustainable?
4. What are the requirements for accommodation in NSW over the next 10 years?

“ You very rarely see people go away from their family for five weeks. Radiotherapy is very effective, but over a distance, hard for people from lower socio-economic groups to access.”

– Palliative Care Nurse

Methods

Investigations included document, literature and internet searches. Stakeholder input from:

- Patients and Carers. Forty-one patients and 26 carers were interviewed.
- Accommodation Providers servicing people from NSW during cancer treatment. Sixty-nine providers contributed.
- Accommodation Providers in South Australia, Tasmania and New Zealand.
- Health professionals. Thirty-five health professionals including Surgeons, Radiation Oncologists, Area Health Service Cancer Care Coordinators, Social Workers (oncology and other), Cancer Care Nurses, Nurse Unit Managers, Palliative Care Nurses and Senior Planners were interviewed.
- The Social Workers Oncology Group (SWOG).
- Cancer Institute NSW Psycho-oncology and Cancer Nurse Coordinator Forums.

The majority of methods were qualitative and exploratory.

(1) AIHW & Australasian Association of Cancer Registries. Cancer in Australia 2006. Australian Government June 2007

(2) AIHW, Cancer Australia, Australasian Association of Cancer Registries. Cancer survival and prevalence in Australia. 22 August 2008

(3) Australian Institute of Health and Welfare. Cancer Incidence Projections Australia 2002-2011. August 2005.

Cancer and remoteness

Cancer survival reduces with geographical remoteness ⁽¹⁾. Survival is also lower for people living in low socio-economic areas compared with areas of higher socio-economic status ⁽²⁾. Remoteness and financial disadvantage are often combined.



“ We’ve been here three and a half months. My partner has been in hospital all that time. I don’t know anyone in Sydney. The people in the lodge are like a family. I’ve no idea where I would have been otherwise.”

– Focus group participant

Demand for accommodation is growing faster than cancer incidence

Cancer is the leading cause of death in Australia and the incidence and prevalence of cancer is predicted to increase over coming years with the ageing of the population. From 2001 to 2011, new cases of cancer are predicted to increase by 29% for women and 32% for men.⁽³⁾

Key findings

The report contains 14 recommendations for improvement in six key areas.

Capacity falls short of demand in Central Sydney, North Sydney and Newcastle. Most regional base hospitals also require additional capacity.

On-site hospital-allied facilities report high occupancy with an average room occupancy rate of 81%.

Although most facilities are of a low to medium standard, the patients who stay in them are generally satisfied with their experience. Affordability is a primary consideration.

Patients and carers identified the features of ideal hospital-allied accommodation as:

- close to treatment
- affordable
- easily accessible for people with restricted mobility
- clean and self-catering
- access point for peer support.

There was also a strong indication that on-site management is important.

Financial issues were of concern to many patients

Partial reimbursement of accommodation and travel costs available through the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) for people living more than 100 kilometres from treatment was inconsistently accessed. IPTAAS is complex and reimbursement rates are minimal. People living less than 100 kilometres from treatment reported considerable out-of-pocket expenses for travel and accommodation. There is no provision for assistance with these costs, borne directly by patients.

Where accommodation facilities are able to “bulk bill” IPTAAS entitlements and the facility agrees to provide the room at a maximum of \$46 per night, patients can stay with minimal cost. Many facilities source income in this way. While this is sufficient to sustain an established non-commercial facility without debt, it is insufficient to support any business case for borrowing capital to fund construction of new facilities.

A constant issue which emerged in the review, for patients in both rural and remote areas and outer metropolitan areas is the need for affordable transport.

Better coordination of travel and accommodation needs is necessary. Health professionals are often required to arrange urgent transport and accommodation. Doing this well during a time of high stress is essential to the well-being of the patient.

Improving access to treatment and support for Aboriginal cancer patients is also an important priority.

As more radiotherapy treatment facilities are established across NSW, additional accommodation needs to be established nearby. Predicting the number of beds required in new accommodation facilities is difficult for a number of reasons. Collaborative approaches to developing accommodation for a broader range of patients and carers are required in regional areas.

Growth in our aged population will contribute to an increase in co-morbidities in people affected by cancer. Not only will there be more cancer patients, they will have more complex needs.