

PROVIDING ACCOMMODATION SERVICES FOR RURAL CANCER PATIENTS: THE EXPERIENCE IN SOUTH AUSTRALIA

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Abstract

People from rural and remote areas face additional psychological and financial burdens associated with the need to travel for cancer treatment and follow-up. To reduce these burdens, The Cancer Council South Australia has established an affordable accommodation service that provides a friendly, homely, supportive environment, where people from non-metropolitan areas can stay while accessing treatment services in the city. The model adopted is very similar to the concept of 'hope lodges' advocated by the International Union Against Cancer, in that it focuses on the needs of guests.

A key aspect of the service is the provision of practical and psychosocial support. Support is provided through a variety of avenues; a qualified social worker on site, trained volunteer visitors, social and recreation programs to encourage informal peer support and transport to major treatment centres. These services are available to people with cancer, their carers and any family or friends staying with them.

In our experience, this model of providing accommodation services to rural cancer patients is both extremely popular and financially viable, and we would encourage other relevant organisations to consider developing similar services where there is an identifiable need.

In many countries around the world, people with cancer often face difficulties accessing effective care because of long distances to treatment centres.¹ This is true for Australia where it is estimated that approximately 30% of all people with cancer live outside a major population centre.² Rural and remote residents experience more problems and concerns associated with travel for treatment and follow-up care, than their peers who reside in urban or regional cities.

A person's sense of isolation is compounded by significant economic and social costs, relating to transport, accommodation and being physically separated from family and friends for considerable periods of time.^{3,5} Time spent away from home for cancer care is also disruptive of family life, work and daily routines and can lead to feeling burdensome to other people.⁶

The concept of 'hope lodges' is emerging as a highly effective community-based solution to many of these identified needs.⁷ Originally developed by the American Cancer Society, hope lodges are designed to provide low-cost or free accommodation to cancer patients and carers, and where resources permit, integrate psychosocial support such as access to counselling and social work. Lodges of this kind offer a friendly, convivial environment, where people with cancer, carers and families can share experiences and support one another through what is often described as a life changing experience. Lodges are usually run by not-for-profit

associations with links to hospitals or other health networks. Recently, the International Union Against Cancer (UICC) has promoted the establishment of hope lodges globally, with lodges now established or being developed in the US, Canada, France, Tunisia and Turkey. The UICC has developed a publication to assist interested organisations to set up hope lodges in their local area.⁸

The Cancer Council South Australia has owned and operated an accommodation service for rural cancer patients for over 10 years, along much the same model as the hope lodges. This paper describes the South Australian experience of providing accommodation services to people living outside the metropolitan area who need to access cancer care in Adelaide.

Historical perspective

In 1995, The Cancer Council South Australia purchased the Parkway Motel (a 55-roomed complex), adjacent to The Cancer Council office in the inner suburbs, now known as Greenhill Lodge, to provide accommodation for rural and remote South Australians.

During the first five years of operation, accommodation requests increased to the point where Greenhill Lodge was unable to meet the demand. In June 2001, the service was expanded with the purchase of Seaview Lodge. This facility consists of nine self-contained units, three kilometres from the main office on Greenhill Road. These units are self-catering and best suit families, long-

term patients and those who may need isolation due to suppressed immune function. While Seaview Lodge guests can access all the services available at Greenhill Lodge, they are required to have their own transport and be more independent as there are no staff located on site.

Following the purchase of Seaview Lodge, priority was placed on improving services for guests at both lodges. The most significant development was the appointment of a social worker to work across both sites. The support coordinator position was established in response to both the research literature and community feedback. Evidence from the literature indicates that psychosocial interventions are associated with improved physical and psychological outcomes for people affected by cancer.⁹ Consultations conducted by The Cancer Council in 2000 with rural cancer patients identified a need for better liaison between metropolitan services and rural communities (internal report).

In 2003, the Board again reviewed future accommodation needs. Findings indicated that The Cancer Council was likely to meet the demand from rural and remote South Australians attending for radiotherapy for the next five years, but would need to increase capacity to cater for other cancer care needs (eg. investigation, assessment, chemotherapy, follow-up care), as well as clients coming from Mildura (Victoria), Northern Territory and Broken Hill (NSW). In light of this, the Board began investigating opportunities to expand the current style of accommodation and support. In July 2006, The Cancer Council South Australia purchased another 75-room motel complex adjacent to the city, which is currently being developed along the lines of Greenhill Lodge. Once this facility is fully operational the total capacity will be 130 rooms.

The facilities and services

Support services

Cancer patients who feel well supported, tend to have better health outcomes and cope better with having cancer.⁹ Particular importance is placed on ensuring a supportive environment for people who are a long way from their normal support networks. A half-time social work position was introduced in 2003, whose primary objective is to provide coordinated support to individuals by assessing and identifying their needs and responding to them appropriately, through advocacy, advice, counselling or referral. In addition to responding to all individual guest's needs, the support coordinator's role includes coordinating volunteers, developing recreational programs to enhance the supportive environment at the lodges and networking with other providers to improve information and service provision.

On average, the support worker assists around 300 cancer patients and 170 carers per year. The role involves ongoing contact with allied health professionals and other relevant agencies in relation to specific guests' needs. Advocacy occurs at both an individual

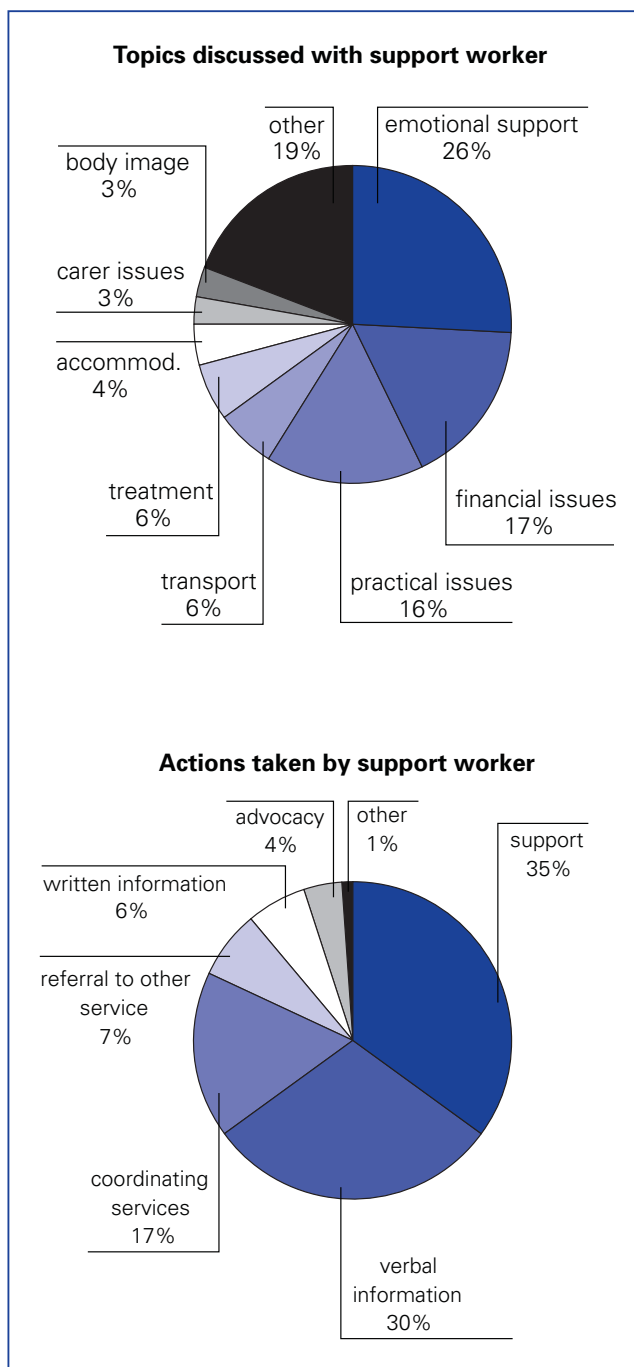
level and a systemic level to address issues of access and equity.

The main reason patients and carers contact the support worker include:

1. psychosocial/emotional support;
2. help with financial difficulties; and
3. practical/informational assistance.

In response, the support worker assists either directly through counselling, providing verbal or written information and/or coordinating services, or indirectly through referral (Figure 1). Trends over the past three

Figure 1. Support worker's activity profile
Data from contact records (July 2003 – May 2006)



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years indicate an increase in face-to-face meetings with guests in regard to emotional and financial issues.

In addition, guests also have access to the full range of information and support resources and programs offered by The Cancer Council, which is located next door or within a five minute drive.

Volunteer programs

The support worker coordinates and supervises a group of volunteers, including friendly visiting volunteers who meet with guests on a weekly basis and provide social contact and practical assistance ie. transport to other appointments or shopping. They also facilitate links with other services as needed.

Volunteers are involved in providing recreational activities such as cooking classes, art classes or event-based functions such as the Melbourne Cup lunch. Activities are held in the recreation room at Greenhill Lodge and are open to patients and family members. Activities such as craft and cooking are hosted by volunteers with skills in a specific area, who are often personally affected by cancer themselves, and occur on a weekly basis. Weekend bus trips are also provided to extend support to those people who cannot travel home for the weekends or are isolated from family and friends. These are often run by a couple of volunteers who, with the assistance of The Cancer Council staff, develop a program of excursions to local attractions around Adelaide.

All volunteers undergo an induction training program when joining The Cancer Council. Skill development workshops are held at regular intervals (approximately three per year) and cover topics such as communication, aspects of treatment and dealing with loss and grief. They are open to volunteers across the organisations who have contact with people affected by cancer eg. peer support volunteers. Accommodation service volunteers also receive regular ongoing supervision and support for the support worker.

Transport service

The Volunteer Transport Service was initiated in 1995 to provide practical assistance with transport to and from the main treatment centres in the city. A bus service has operated from 8am-5pm Monday through Friday consistently since then, with three volunteers each doing a three-hour shift per day. This service was expanded in October 2002 to transport guests to a treatment facility 15km south of the city. This service offers one trip in the morning and one in the afternoon. Currently there is a contingent of 37 volunteer drivers.

Dining room service

The cost of eating out when away from home can be a considerable burden. Furthermore, it is not uncommon for people having treatment for cancer to experience side effects that may cause difficulty in eating, including loss of appetite, nausea and difficulty in swallowing, which can lead to poor nutrition and undesirable weight loss. It is therefore important that patients maintain a varied and balanced diet of high nutritional value.

To help address these issues, Greenhill Lodge provides dining facilities for guests in the evening and a communal kitchen for self-catering throughout the day. The two-week rotational menu at Greenhill Lodge ensures a balance of all the food groups, with an emphasis on vegetables and fruit at every meal. Meals are deliberately high in calories to ensure adequate nutrition for patients undergoing cancer treatments. The menu also includes a majority of 'traditional' meals such as roasts, as these dinners are found to be popular with guests from regional areas.

Another option for guests is to use the communal kitchen where food can be stored, prepared and enjoyed from 8am to 8pm, seven days a week. This facility not only allows flexibility for patients and their carers, but also provides a meeting place for guests to interact and socialise.

Smoke-free policy and quit support

Passive smoking has been a problem for guests in the past. Recent improvements have been made to ensure a smoke-free environment and quit smoking support is available at Greenhill Lodge. There is a designated outdoor smoking area in a central location. Signage has been placed outside each room and at the entrance of Greenhill Lodge, clearly identifying the designated smoking area and reminding patrons and visitors that the accommodation facilities are smoke-free.

Providing quit smoking support and a smoke-free environment are key strategies of The Cancer Council to reduce the harm caused by smoking. Guests have access to the Quitline service which is available by ringing an internal extension. This service is available from 9am-8pm weekdays and 2-5pm weekends and public holidays.

Managing the service

Running a facility such as Greenhill Lodge is based on the same principles as a commercial accommodation facility, with standard operating procedures relating to reservations and services offered. The ambience of the property is purposely designed to create a homely atmosphere. The major difference between commercial facilities and the lodges is the level of understanding needed by employees in relation to guest needs. This applies to housekeepers, volunteers, catering and reception staff. To equip staff with skills to relate effectively with guests, a specialised training program was developed for accommodation services. Delivered over two sessions to staff from all sections (catering, housekeeping and reception), the program focused on developing empathetic communication styles. It also emphasised the need to recognise when guests need additional support and refer them to professional support services (ie. the social worker).

No medical services are offered or available. Guests are required to be able to care for themselves, or have a carer present at all times. Whilst staff are present at Greenhill Lodge 24 hours a day, emergency situations are handled by phoning an ambulance. The response time is approximately seven minutes.

Occupancy at Greenhill Lodge now averages in excess of 90% per annum. A commercial hotel of this size would be closer to 65%. This places considerable stress on the resources, both human and physical (Figure 2).

Financial aspects

The operation of a facility such as Greenhill Lodge has required a careful balance between viability (a balanced budget) and the need to cater for the special needs of cancer patients and carers. In most cases, the patient and carer have no out-of-pocket costs relating to accommodation. This is covered through federal and state government funding programs such as the Patient Assistance Travel Scheme (PATS),¹⁰ or the equivalent in other states. The South Australian scheme provides financial assistance to people residing 100km or more from the Adelaide CBD who require care at a metropolitan health service. Room rates for guests who qualify for PATS do not exceed the current level of reimbursement (\$30 a single/\$60 a double). Room rates

are reduced for guests who require cancer-related care, but do not qualify for PATS because they live within the 100km limit. Commercial guests, including regular clients from a number of service organisations, are accepted when the facility is not fully occupied by non-commercial guests (for example on weekends when many guests return home), at standard rates comparable to similar motels. This system is carefully managed to ensure that commercial guests are aware and respectful of the needs of guests who have a cancer diagnosis.

Maintaining a high occupancy rate is an important factor in the financial viability of operating such a service. Trends over the past seven years indicate the ongoing profitability of this model of operation (Figure 2). A cash surplus allows for the provision of extra services not normally associated with a commercial operation and the ongoing upgrading of facilities.

The accommodation facilities also provide a focal point for various fundraising events undertaken by The Cancer

Council South Australia branches. Sixteen of the 17 branches are located in rural areas of South Australia, hence potential donors can see direct links and benefits for their communities. Accommodation services have been a central theme in rural doorknock appeals in the past and continue to be promoted in relation to other major Cancer Council events in regional areas eg. Daffodil Day. Individual branches also run their own local events with specific fundraising objectives. For example, one rural branch held a concert to raise money to purchase an additional bus for Greenhill Lodge. A large number of donations are also received from former guests and family members, either directly or through in memoriam donations and bequests, with a request that they be directed toward further improving accommodation facilities. In-kind donations are also offered by both individuals and service clubs, for example labour/supplies to renovate several rooms. Formerly, substantial donations were acknowledged and recognised through dedication of individual rooms. More recently, donations are recognised via individualised engravings that form part of a sculpture located in the garden at Greenhill Lodge.

Figure 2. Expenditure, income and percentage occupancy (1999-2005)

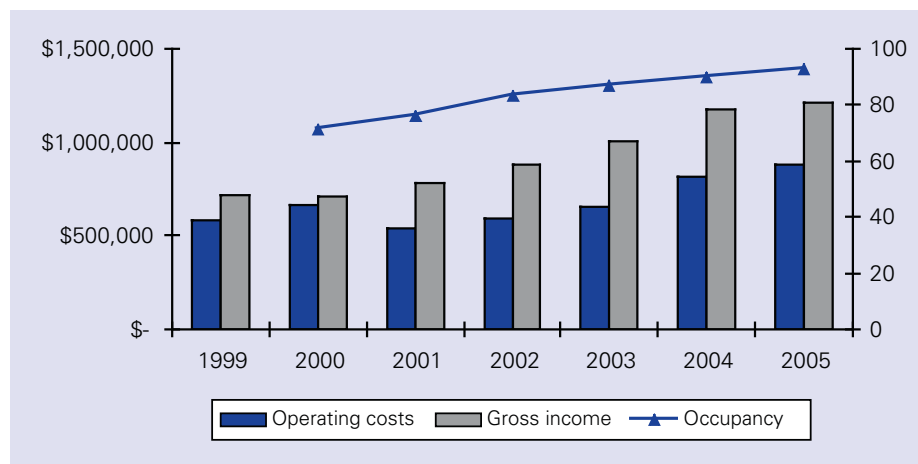


Figure 3. Length of stay and per cent having radiotherapy (2000-2005)

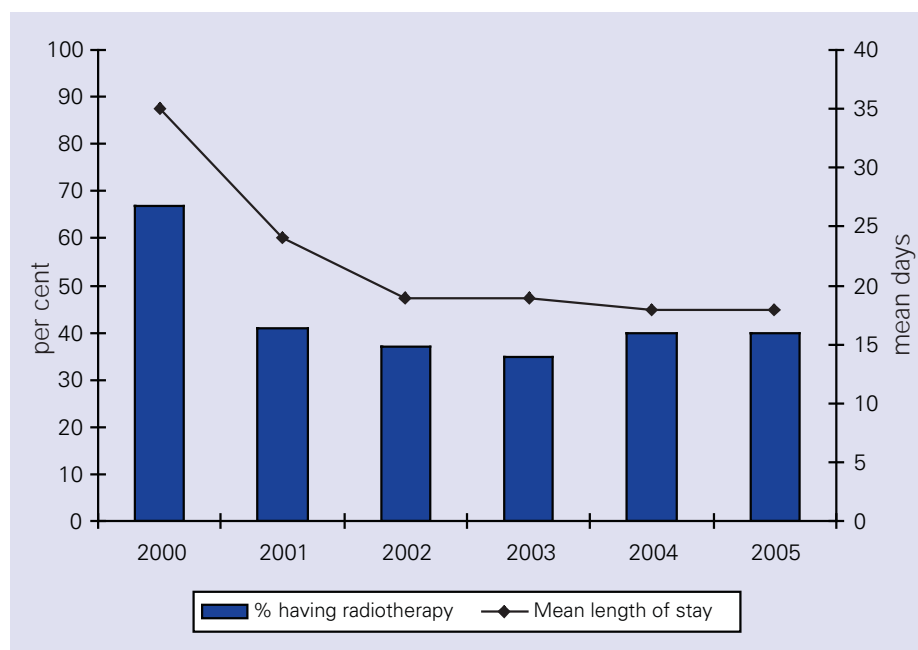


Table 1. *Guests' use of services at Greenhill Lodge*
Data from guest feedback surveys 2001-2005

Use of support services at Greenhill Lodge <i>Per cent of Greenhill Lodge survey respondents (2001-2005)</i>	Short stay <7days (n=218)	Longer stay 7days+ (n=210)	All guests (n=451)
Used bus/transport service	45	75	59
Used dining room service	60	69	65
Used guest kitchen	44	73	57
Used recreation room	25	48	36
Used information directory	82	84	83
Had contact with friendly visitor	19	51	34
Had contact with support worker	15	43	27
Attended recreation program	8	32	20
Used Cancer Council services/resources	18	33	24

Table 2. *Helpfulness of services at Greenhill Lodge*
Data from guest feedback surveys 2001-2005

Helpfulness/convenience of Greenhill Lodge services <i>Per cent of guests surveyed who used service</i>	Very good or good
Helpfulness of the friendly visitor program (n=84)	92
Helpfulness of the support worker (n=63)	95
Rating information and recreation programs (n=84)	98
Convenience of accommodation services (n=444)	99
Convenience of guest kitchen (n=282)	99
Reliability of transport service (n=296)	100
Usefulness of the information directory (n=355)	100

Evaluation and continuous improvement

Surveys of guest satisfaction at Greenhill Lodge have been undertaken annually since 2000, as part of The Cancer Council's commitment to continuous improvement. Each year, all non-commercial guests staying at Greenhill Lodge during a specific month are sent a postal survey, four to six weeks after their stay, which they could complete and return anonymously. Response rates have ranged from 65% to 78%. Due to the smaller number, only one survey of Seaview Lodge guests has been undertaken.

Trends indicate a change in the profile of Greenhill Lodge guests over the past six years, with significant decreases in both the mean length of stay (35 days in 2000, compared with 18 days in 2005) and the proportion receiving radiotherapy while at the Lodge (67% in 2000, compared with 40% in 2005). In 2005, only 30% of those surveyed were first time guests (Figure 3).

Satisfaction with the facilities and services has been consistently high. Of the 568 guests surveyed in total, 566 (99.7%) indicated they would stay at Greenhill Lodge

again in the future. All guests indicated they would recommend Greenhill Lodge to others.

Feedback indicates that the provision of services to address guests' practical and emotional needs is a highly valued aspect of the service. In 2005, nearly three quarters of all guests had made use of the bus to access treatment facilities (72%). Sixty-six per cent had used the dining room and 62% had used the guest kitchen during their stay. A smaller proportion of guests had accessed the recreational facilities (40%) and recreational programs (18%) (Table 1). However, almost all of those who attended recreational programs rated them very highly (98%) (Table 2). Approximately one third of guests utilised supportive care programs, 35% had contact with the friendly visitor program and 32% had contact with the support worker. Guests who stayed for an extended period (one week or more) had made greater use of the various practical and supportive services than those staying for shorter periods.

Guest feedback has led to continuous improvements in the facilities and services provided at the lodges. For example, the kitchen facilities have been upgraded and

Table 3. *Guests views on smoking restrictions at Greenhill Lodge*
Data from guest feedback surveys 2001-2005

Policy re smoking at Greenhill Lodge Per cent of guests surveyed	2003 (n=85)	2004 (n=70)	2005 (n=91)
Smoking banned	18.8	28.6	30.8
Smoking in designated areas	56.5	52.9	57.1
Smoking allowed anywhere outdoors	24.7	18.6	12.1

larger fridges placed in rooms, in response to guests' desire for more self-catering options. Room upgrades have incorporated guests' suggestions where possible. Additional information has been added to the information directory, reflecting guests' needs. Greater restrictions have been placed on smoking at Greenhill Lodge in light of a notable shift in attitudes and numerous negative comments about exposure to others' "second-hand" smoke (Table 3).

Seaview Lodge guests rate the facilities as highly as those at Greenhill Lodge. While the self-catering style was preferred by many, a few guests felt isolated and unsupported at Seaview Lodge. This feedback has led to a stronger commitment to ensuring Seaview Lodge guests are aware of and have access to support services at Greenhill Lodge.

Conclusion

The Cancer Council South Australia has been committed to supporting rural communities through the provision of affordable, supportive accommodation for rural patients and their families.

The model adopted by The Cancer Council South Australia has proved to be highly successful, both in terms of its popularity with guests and as a viable financial venture. In our experience it is possible to provide a quality accommodation service and return a profit, which can be utilised to continually improve facilities for guests. Success has been due to sound financial management, continuing growth in demand, ongoing evidence-based improvements, well-integrated support services and strong community support for such

a service.

In light of our positive experience, The Cancer Council South Australia endorses the concept of hope lodges. We encourage other organisations interested in supporting people with cancer (or other medical conditions) to consider establishing similar facilities where there is an obvious need.

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