

# Relocation for treatment for leukaemia: A description of need

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## Abstract

*As rural Queenslanders are isolated geographically due to dispersed population patterns, they are often required to travel long distances to access services, especially services of a specialist nature. The distress of this relocation for treatment is particularly intensified for patients with leukaemia and associated haematological disorders and their carers, as they must often relocate for long periods of time and face invasive and demanding treatments away from the comfort of their own homes. Because such treatments are now highly technical and specialised, even patients from more urbanised areas are also required to relocate for prolonged specialist treatment not available locally. Consequently, for many rural and urban patients with leukaemia, relocation for specialist treatment is a major concern.*

*This discussion presents findings from recent research on a Queensland Government initiative, the Patient Transit Assistance Scheme, designed to address this concern. These findings indicate a high level of hardship for these patients and their families who must travel long distances, often relocate for long periods, and endure additional financial burdens at a time when a majority are dependent on government assistance.*

## Introduction

Australian health care services, especially specialist services, are disproportionately concentrated in major urban areas (Humphreys & Murray 1994). There is a large variation in population density and vast areas of extreme sparsity (Holmes 1977) that make the provision of health services to rural and remote parts of Australia difficult (Cheers 1990). Consequently, as rural Queenslanders are isolated geographically due to dispersed population patterns, they are often required to travel long distances to access services, especially services of a specialist nature

(Australian Institute of Health and Welfare 1996; Keleher & Ellis 1996). This isolation is associated with significant economic and social costs, in terms of the time and money associated with transport, and the disruptions to daily routines that may result from long-term treatment which requires the patient to be physically separated from family and friends for considerable lengths of time (Eyles & Smith 1995). Because of the lack of local health facilities, rural and remote area residents can only obtain adequate medical care at considerable cost to themselves and/or their sources of support (Humphries 1985). This situation is intensified for the more needy, who have even greater access problems (Australian Government Commission of Inquiry into Poverty 1974). Understandably, Veitch's work (1995) indicates that geographical distance is associated with the experience of anxiety in relation to health care.

The distress is exacerbated for patients diagnosed with leukaemia and associated haematological disorders. These diagnostic groups have a myriad of particular and distressing problems (McGrath, in press, a). The most relevant of these problems, in relation to this discussion, is that they must often endure lengthy, risky, invasive and demanding treatments that necessitate long stays away from home for both the patient and their carer (Patenaude 1990; Baker, Curbow & Wingard 1991; Grant et al. 1992; Bertero & Ek 1993; Stalfelt 1994; Whedon & Ferrell 1994; Leigh et al. 1995; Molassiotis 1995; Thain & Gibbon 1996). Because such treatments (high-dose chemotherapy and bone marrow transplantation) are now highly technical and specialised, even patients from more urbanised areas are also required to relocate for prolonged specialist treatment not available locally. Consequently, for many rural and urban patients with leukaemia, relocation for specialist treatment is a major concern.

As yet, as far as I am aware, there is scant research, either nationally or internationally, conducted on the experience of relocation. With only a few exceptions (Langlands 1993; McGrath, in press, b), very little work is being carried out on accommodation for cancer patients, particularly those with haematological disorders, and even less with regards to issues associated with transportation, carers or families during relocation.

As one response to this gap in research, this discussion presents recent Australian data on a wide range of issues associated with relocation of patients for treatment for leukaemia, including distances travelled, demographics of carers, and welfare dependence within the patient population. This material will provide some indication of the magnitude of the problems for those needing to move to the metropolitan area for treatment. These findings are part of a wider study on the Patient Transit Assistance Scheme in relation to patients with leukaemia and associated haematological disorders undertaken at the

Centre for Public Health Research, Queensland University of Technology. This scheme is one of Queensland Health's initiatives designed to facilitate equal access for Queensland residents to essential health care services. By contributing to the cost of transport and accommodation, this scheme provides direct assistance to patients, and in some cases their carers, to attend specialist medical services not locally available.

The present data indicate that there is an extensive need for accommodation and travel assistance for those families touched by the serious diagnosis of leukaemia or associated haematological disorders. The findings from this seminal work in the area of travel and accommodation for cancer patients strongly indicate that this is an important topic that deserves increased research attention.

## **The Patient Transit Assistance Scheme**

The Patient Transit Assistance Scheme provides direct assistance to patients and, in some cases, their carers so they can have access specialist medical services from which they are isolated. This scheme has been put in place to help all Queenslanders, irrespective of whether they live in metropolitan centres or isolated areas, to have access to specialist medical services. Where such services are not available within 100 kilometres of the nearest public hospital, the scheme will make a contribution towards the cost of transport and accommodation. If it is essential for the patient's treatment that someone should travel with them, a contribution can also be made to the cost of the escort's transport and accommodation.

Originally this system was instigated by the Federal Government as the Isolated Patients Travel and Assistance Scheme and administered by Commonwealth officers. In 1986 the Commonwealth ceased to provide this scheme and handed over the funding for the program to the States. In Queensland the scheme was retitled the Patient Transit Scheme. Block funding was provided to ensure financial subsidies to cover the cost of patient travel by the cheapest available means of transport to specialist treatment, and assist with the cost of accommodation if required. Initially Patient Transit Scheme funding was centrally processed in Brisbane and was transferred to the Regional Health Authorities when they were established.

Although those who know about the scheme have been appreciative of the concept, there have, unfortunately, been extensive difficulties in relation to its implementation, generating widespread concern about issues of equity and access. Consequently, in 1991 the scheme underwent reviews that led to

modifications. The name of the scheme was changed to Patient Transit Assistance Scheme to emphasise the partial rather than complete support for travel funding.

In 1993–1998, through the Medicare Agreement, Queensland was committed to ensure equity of access to health services for isolated persons. This was to be achieved by either providing all required services at all recognised hospitals or by accepting responsibility for transferring the patients to locations where such services are available.

This scheme is administered decentrally through a complex set of arrangements involving travel clerks, specialists, and medical superintendents at regional referring hospitals and corresponding staff at metropolitan treating hospitals. Perhaps because of the decentralised nature of the administration of this scheme, there is no central database where exact details of annual expenditure, number of subsidised trips, patients or escorts are available. Rough estimates of expenditure, however, suggest that the cost of this scheme in Queensland is annually around \$14 million. The Patient Transit Assistance Scheme is thus a very important Health Department initiative, centrally concerned with significant issues of equity and access to health care, that touches the lives of many Queenslanders at the most vulnerable time in their lives. It is thus of some concern that although a great deal of controversy and public comment exists on this scheme, *to date there has been no academic research on the system*. The present research carried out by the Centre for Public Health Research is seminal work in this area.

## Research on the scheme

The overall aim of the research is to document the significant issues associated with the administration of the Patient Transit Assistance Scheme in terms of the importance of this service to patients and their carers. To achieve this aim it is necessary to disaggregate the overall project into five closely interrelated but smaller arms covering a variety of issues, including decision-making (Arm A), non-referrals (Arm B), significance of the scheme to patients and their families (Arm C), financial issues (Arm D), and a descriptive profile of those successfully accessing accommodation (Arm E). The findings from the five arms of this research will provide an overall picture of the administration and significance of the scheme. Together, the five arms will contribute significantly to our understanding of how the Patient Transit Assistance Scheme is administered, whom it does and does not support, and its psychosocial and financial significance to patients and their carers.

The present findings are from Arm E of the research. This arm of the research focused on data available from the very successful Brisbane accommodation centres for patients from these diagnostic groups run by the Leukaemia Foundation of Queensland (LFQ). Full details of these centres and the work of LFQ have been published elsewhere (Hartigan 1996; McGrath, in press, a and b).

### **Study sample (Arm E)**

This section of the study (Arm E) analysed data on all patients and their carers accommodated at the LFQ accommodation centres during the calendar year of 1997. LFQ has three accommodation complexes (Herston, ESA Village and Holydene) that collectively have 38 units to accommodate families. The patients and their carers come from all over Queensland, as well as interstate and overseas. On occasions, LFQ extends support to patients who have been diagnosed with a condition other than leukaemia or the associated haematological disorders. There will be a subset of patients with breast cancer and brain tumours. Patients have been included irrespective of their age, gender, length of stay, diagnostic group or family composition. The arbitrary cut-off date for the collection of data is from 1 January 1997 to 31 December 1997.

### **Data collection and analysis**

The data for this descriptive profile have been obtained from the admission forms that are filled out when the patient arrives at one of the LFQ centres. The data are fairly complete for the first visits, but not so for subsequent visits. There was, however, missing data and this is acknowledged throughout the presentation of findings. The administrative officers, who completed the admission sheets and were still in contact with many of the patients, were available to fill in many of the gaps in information. Consequently, although the data were not obtained through a specifically designed research instrument, the extent of information provided could be likened to obtaining a 100% response rate on a questionnaire.

One hundred and forty-six variables were developed from the categories on the admission sheet. This material was alpha-numerically entered into the Q-edit statistical package and quantitatively analysed with simple descriptive statistics (univariate and bivariate).

### **Findings**

The data provide evidence of the strain on family resources arising from the need to travel to specialist treatment. The data document the experience of relocation as involving not only patients but also the nuclear family, including children,

extended family and friends. For all these participants there will be the stress of leaving the familiar, of interruption to education or work, of maintaining homes *in absentia*, and of incurring the many incidental costs of relocation. This process includes family members at all stages of life from young children to the elderly.

### Distances and places of residence

LFQ accommodated 204 patients in the calendar year of 1997 from destinations throughout Queensland (n = 184), as well as interstate (n = 17) and overseas (n = 3) (McGrath, in press, b). Patients came from towns all over the State, often from very rural and remote areas, along the coastal strip and with a strong concentration from the densely populated south-east corner. Of those who came from within Queensland, the distance travelled, which has been calculated on one round trip per patient from town of residence to metropolitan hospital, is 207 473 kilometres. It is evident from this figure that many patients are expected to and do travel long distances. This is an underestimation of the distance travelled as it does not take into account the return trips patients make between visits to the accommodation centres which, as previous research indicated (McGrath 1998b), can be up to as many as seven. Table 1 demonstrates that a majority of patients (53.4%) have to travel long distances of over 500 kilometres. A few (3.3%) came from within a 100-kilometre radius of Brisbane, and are still accommodated at LFQ centres although they will not be in a position to claim from the Patient Transit Assistance Scheme.

**Table 1: Distance travelled (round trip) by clients who resided in Queensland**

Distance (km)	Percentage of sample
0-250	36.1
251-500	10.4
501-750	10.4
751-1000	1.1
1001-1250	2.7
1251-1500	8.7
1501-1750	0.5
1751-2000	10.9
2000 +	19.1

## Reliance on government benefits

Although occupational status and socioeconomic details are not available on this group of patients, some idea of the hardship these families face is provided by the statistics in Table 2 of those relying on government benefits (for example, Sickness Allowance, Disability Pension, Sole Parents Pension). The data indicate that patients across all age groups depend on government benefits. Overall, approximately two-thirds of the clients (65.6%,  $n = 128$ ) were receiving some form of government benefit. The proportion in receipt of government assistance varied considerably by age, with the rates being higher in the younger (0–30 years) and older (65 years or more) groups. It is particularly notable that over 50% of clients in each age group were receiving government assistance at the time the data were collected.

## Treatment centres

There were eight treatment centres that patients attended including the Mater, Royal Brisbane, Royal Children's, Wesley, Princess Alexandra, Greenslopes and Holy Spirit Hospitals and the Queensland Radium Institute. Patients were attended by 27 specialists, concentrated predominantly at the Royal Brisbane (46.1%), Mater (38.7%), Wesley (11.3%), Royal Children's (2.5%) and Princess Alexandra (1.5%) Hospitals. The LFQ accommodation centres are within walking distance of two of the major treating hospitals.

**Table 2: Patients on benefits, by age**

Age	Frequency	Percentage of total population	Percentage of benefit population
0–9	6	3.08	4.69
10–19	12	6.15	9.38
20–29	17	8.27	13.28
30–39	23	11.97	17.97
40–49	24	12.31	18.75
50–59	22	11.28	17.19
60–69	18	9.23	14.06
70+	6	3.08	4.69
<i>Total on benefits</i>	132	65.7	
<i>Total not on benefits</i>	69	34.3	
<b>Total population</b>	<b>201<sup>1</sup></b>	<b>100</b>	

1. Data unknown for three cases.

### Those accompanying the patient – escort, carer and family

By far the majority (89.7%) of patients had escorts and these were predominantly female (68.9%) (McGrath, in press, b). Clients not accompanied by an escort ( $n = 21$ ) were aged between 25 and 67 years (mean 45.4, sd 10.6) and most (66.7%,  $n = 14$ ) were male. When the data on escorts are disaggregated by age (Table 3), the major concentration (56%) is parents in the younger group under 19 years of age (although well represented throughout the distribution); partners spread throughout the ages of early to late maturity (20+); and friends represented in the adult years. Although female carers were in the majority, it is interesting to point out that there were more male parents (27.2%) than female parents (16.4%).

Children were the exception rather than the rule, with only 11.4% of families accommodated with children (McGrath, in press, b). A breakdown of the data shows that there is a wide spread of ages of patients with children but it is concentrated in the nurturing years of parenthood from 20 to 49 years.

**Table 3: Escort in relation to age of patient**

Relationship	Age in years								Total
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70+	
Male partner	0	0	4	8	12	13	5	3	45
Female partner	0	0	6	16	13	16	12	3	66
Daughter	0	0	0	0	0	2	0	0	2
Son	0	0	0	0	0	0	1	0	1
Friend/significant other	0	0	1	1	1	1	1	0	5
Brother/sister	0	0	0	0	1	3	1	0	5
Parent	9	14	9	4	4	1	0	0	41
Don't know	0	1	1	1	5	2	3	0	13
<b>Total</b>	<b>9</b>	<b>15</b>	<b>21</b>	<b>30</b>	<b>36</b>	<b>38</b>	<b>23</b>	<b>6</b>	<b>178</b>

*Note:* Of the total patient population of 204, only 183 had escorts and, of these, in 5 cases the relationship to the patient was unknown.

## Discussion

Support workers at the Leukaemia Foundation see on a daily basis the impact of relocation for specialist treatment for leukaemia, which engages patients and their families in a process involving considerable hardship. Families are split.



Children either have their schooling interrupted or are left behind. Adults must weigh the demands of employment against the desire for togetherness. At least one member of the family or a friend must interrupt their life to be available to escort and care for the patient. Families are forced to adjust quickly to the demands of separation, the alien and at times alienating world of an unfamiliar metropolitan city and its busy major hospital, and the psychological trauma of coming to terms with a member having a life-threatening illness. Extra financial demands are placed on families because of the expenses incurred during trips away from home, and the need to maintain their home whilst absent. Pets must be provided for, businesses and farms kept running, and arrangements made for the care of dependent relatives. All of this must be organised at very short notice, for most patients are sent immediately on diagnosis to specialist metropolitan treatment with a minimum of warning.

The findings from this research begin to document this experience by providing some indication of the extensive number of families affected by such relocation, the long distances they travel, the financial hardship, and the extensive impact on, and involvement of, carers and families in the experience. The figures represent a profile at one point in time of the involvement of children, carers, extended families and significant others in the difficult and demanding process of seeking specialist treatment away from their place of residence. These findings, by documenting the extent of the response to accommodation presently provided by LFQ, raise important questions about what is happening in other locations where such facilities are not available for families.

The figures from this research document the considerable use of accommodation provided for patients relocated for treatment for leukaemia and their families. The data provide important evidence that where such accommodation is made available it is readily and extensively used. Historically, the LFQ accommodation centres were developed on an assumption of patient need. The evidence indicates that this need is profound, with many families having to travel long distances for treatment, return many times to the specialist centres, and stay away from their home towns for lengthy periods of time.

The relocation for most patients will mean that at least one other person will have to dedicate time out from their current life to act as an escort. For the unfortunate few, even this resource is not available. This process will be happening at the vulnerable time when patients and their families are coping with the facts of a life-threatening diagnosis. The demands of relocation will be in addition to the physical, emotional and financial strain of undergoing difficult specialist treatments.

That these families are experiencing considerable economic hardship is evidenced by the high incidence of patients on government benefits. This situation is a result of a multitude of factors, including unemployment brought about by physical illness, the necessity to leave employment to seek treatment away from place of usual residence, inability to sustain work because of the side-effects of treatment, and prolonged recovery periods. Carers, as well, must face critical employment choices when deciding whether to leave their home town to accompany the patient. Families must carry the full impact of the financial restrictions of living on government benefits at a time when the extra costs brought about by the demands of the illness and relocation are mounting. Facing an economic crisis, along with physical illness, is a very real dilemma for these patients and their families. The prolonged treatment makes this a very drawn-out crisis that is capable of placing very serious strains on a family's ability to function. The statistics indicate that this is happening to both genders along the full continuum of life from youth to the older age group.

These findings record evidence of the need for, and hence importance of, the Patient Transit Assistance Scheme for the many unfortunate Queenslanders who must face long travel distances and prolonged accommodation away from their homes during the difficult and challenging time of undergoing intense treatments at specialist metropolitan centres for their disease. For such patients, the scheme is an essential, rather than a luxury, service. The effective administration of this scheme is essential not only for issues of equity and justice in health care, but also to ensure that patients who must face the burden of such serious illnesses as leukaemia and associated disorders are provided with the basic, humane and compassionate support that is necessary for their well-being and to assure effective treatment outcomes. A consideration of issues associated with relocation is essential for patient care and hence is an important research topic.

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