



Leukaemia
Foundation

VISION TO CURE[®]
MISSION TO CARE

SUBMISSION TO:

SENATE COMMUNITY AFFAIRS COMMITTEE

**INQUIRY INTO THE OPERATION AND
EFFECTIVENESS OF PATIENT ASSISTED
TRAVEL SCHEMES (PATS)**

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An Western Australian Perspective

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Background on the Leukaemia Foundation

Established in Queensland in 1975, the Leukaemia Foundation (the Foundation) is the only national organisation dedicated to the care and cure of patients and families living with leukaemias¹, lymphomas, myeloma and related blood disorders.

The Foundation has a *mission to care* and a *vision to cure*. It does this by providing personalised support and care for patients and families throughout their journey – from diagnosis, treatment to recovery. This support is provided by an extensive team of health professionals including trained cancer nurses, social workers and allied health professionals and reaches every town and community across Australia.

Support services include emotional support; referral to specialist counsellors at no cost; disease-specific information materials; education programs and support groups; access to 'home away from home' accommodation close to major treatment centres; transport to and from metropolitan treatment centres and practical assistance including financial assistance.

The Foundation is also committed to an ongoing funding for vital research into the causes, epidemiology, diagnosis and treatment, psychosocial impact and ultimately cures for leukaemias, lymphomas, myeloma and related blood disorders. In 2006, the Foundation committed more than \$2.4 million in research funding.

Access to Haematology Services Regionally

Throughout regional Western Australia there are extremely limited haematology services available. There is limited low level care available in Bunbury and in Albany. These treatment areas provide only simple administration of chemotherapy. They are not resourced for admissions of an un-well immunised compromised patient.

No haematology patient diagnosed within regional WA would be able to avoid multiple trips to Perth as is evidenced by the following list of diagnostics and treatment that are not available elsewhere.

- All haematologist appointments.
- Scanning and radiology appointments.
- Any nuclear medicine scans.
- Chemotherapy regimes – either preformed as inpatient or outpatient.
- Admission to treat neutropenia infections post chemotherapy.
- Access to specialised physio; dietetics; rehabilitation and psychological health professionals.

¹ For economy of expression, when this document refers to leukaemia it includes the leukaemia, lymphoma, myeloma and related blood disorders such as aplastic anaemic and other less common bone marrow malignancies

Post treatment complications are common, over 70% of haematology patients will have an infection requiring intravenous antibiotics.

Due to the potentially life threatening complications that can occur post treatment, and the necessity of specialist physicians to over see their care, patients are required to stay in Perth for daily monitoring until they recover, on average at least 4 weeks.

At this time most patients require blood and platelet transfusions which are difficult to get regionally.

Once recovered the patient usually begins the next cycle of treatment – long gaps in treatment increases the risk of disease relapse, hence the longevity of treatment requirements and the need to stay in Perth for the duration.

Current Accommodation Provision

Leukaemia patients, carers and their families have unique needs in regards to accommodation services. Average length of treatment for leukaemia is 5-8 months.

Chemotherapy and bone marrow transplantation treatments leave most patients very susceptible to infection and shared facilities are not recommended during treatment and recovery times.

Currently the Foundation has a rental arrangement for fourteen (14) self-contained units situated at three separate Perth metropolitan locations:

- Four (4) units in West Perth
- Six (6) units at Bassendean, and;
- Four (4) units at Coolbellup.

These units primarily accommodate regional leukaemia patients, their carer and family. Over 90% of patients who stay in the accommodation units are from regional Western Australia. Occupancy rates are high, with 90% of accommodation full most of the year. Additional accommodation is at times funded in private hotels/apartments.

Long Term Patients Needs

Leukaemia strikes at the heart of families most often without warning. For those diagnosed in regional and rural WA, transfer to a Perth hospital is paramount for survival. Many patients commence life saving treatments within 48 hours of diagnosis, wrenched from their home, their work and their support of family and friends to begin life saving chemotherapy, radiotherapy and for many, eventual bone marrow transplantation. As stated previously, initial treatment can be for up to 5 months, often followed by a bone marrow transplant that requires 3 - 6 months recovery close to their treatment centre.

The patient assisted travel scheme is not set up to provide long term assistance for patients from rural and regional WA. Ongoing monthly PATS documentation requiring written proof of the patients need to stay in Perth is an arduous task when recovering from treatment. Assistance from Leukaemia Foundation staff is required to ensure the correct paperwork is completed.

It is our belief that many patients do not claim PATS because of the challenging documentation – often for little reimbursement. A recent example was of a patient who had stayed 5 nights in a private hotel between admissions, he medically was unable to return home for these days due to daily tests, but did not require to be an inpatient at this time. As this would be his first claim and he was a non health care card holder, his entitlement was \$70 of his \$395 accommodation bill. This left an out of pocket expense of \$325. Although entitled to claim for \$70, in his opinion the paper work was too difficult to be bothered with while he was recovering from treatment.

If patients are required to stay for longer than six months, the scheme states that patients are required to re-locate to Perth to continue treatment with a rental subsidy offered of \$140 per week. Although this may be a fiscal solution to the short time problem it ignores several points. It is our experience that most patients have the goal of preserving as much of their pre-diagnosis life as possible. They reasonably want their children to stay at their schools; their partner may have a job that is providing the only income and their entire support system is located in their home town.

While they are staying in our accommodation facilities in Perth the psycho-social support patients and their families receive from the leukaemia foundation staff is vital to their ongoing physical and mental wellbeing.

Challenges of PATS in WA

The Leukaemia Foundation concurs with the Cancer Council WA that the PATS is essentially a good scheme but does need to be revisited and updated.

As an addendum to the Cancer Council WA PATS Issues Paper the Leukaemia Foundation patients (in WA) needs differ in the following ways:

- ◆ Leukaemia is an acute illness often demanding royal flying doctor service transfer from remote and rural WA. The acute nature of the illness often precludes the patient from applying for PATS before being brought to Perth for treatment.
 - Retrospective approval is difficult to obtain, is time consuming and frustrating for all persons involved.
- ◆ Patients are only eligible to have a carer or escort accompany them to Perth for medical reasons – what constitutes ‘medical reason’ is sometimes arbitrary depending on the pats clerk.
 - Emotional support for patients by their loved ones needs to be considered in the illness journey, patients staying for long periods of time should automatically be given the option of carer.
 - Descriptive data suggests that adjustment by patients with cancer is enhanced by family and partner support (National Breast Cancer Centre and National Cancer Control Initiative, 2003).

- Being alone in Perth is restrictive and isolating for patients who may stay for up to 8 months. Many country patients are unaccustomed to the city and are therefore confronted with the emotional burden of dealing with their illness and treatment alone.
- ◆ Most patients are only made aware of our accommodation services when they get to Perth and may have been paying full rate in a private hotel/apartment.
 - Despite ongoing updates of our services to PATS clerks, there is evidence that not all patients are receiving information regarding available accommodation.
- ◆ There is a perception that not all GP's refer all patients to pats, especially if they are a private patient.
- ◆ Patients' documentation requirements differ. Patients are sometimes required to provide an updated 'blue form' at the end of each month to extend the LPO. In addition they are *sometimes* required to provide written evidence from their specialist.
 - This is inconsistent depending on the pats clerk and their level of understanding of the patient's circumstances and interpretation of the guidelines.
 - Anecdotal consumer feedback suggests particular PATS clerks make special allowances for certain individuals and therefore there is no standardisation with delivery of PATS.
 - Leukaemia Foundation staff can *sometimes* undertake this arduous task on behalf of the patient, at *other* times only the patient or carer (if approved) can provide this information.
- ◆ After 6 months of continuous assistance the patient is no longer eligible for pats and must return home to re-start the process or relocate to Perth; both are unsuitable options.

Financial Implications of PATS

- ◆ The Leukaemia Foundation provides family accommodation **regardless** of PATS approval to all leukaemia patients and their carers/family members. In WA we receive PATS funding for approximately 70% of patients we accommodate.
- ◆ At no time are any regional patients required to contribute to their accommodation costs whilst residing with the Leukaemia Foundation.
- ◆ The current subsidy of \$35 per night for the patient and \$35 per night for the carer (when approved) is not consistent with the true cost of providing accommodation to country patients.
- ◆ When non healthcare card holders are within their first four trips the Leukaemia Foundation waves this fee – up to \$840 per couple.

- ◆ Leukaemia Foundation accommodation does not provide 24 hour assistance and as such all patients are required to have a carer whilst in our accommodation.
 - Single patients are accommodated externally and the Foundation pays the 'gap' between PATS cover and the accommodation charge –on average \$70 per night or \$2170 per calendar month per patient.
- ◆ The payment of PATS is very slow; it can take up to three months from time of invoice for the Leukaemia Foundation to receive payment. PATS reimbursement is only provided once the patient has returned home. As most of our patients stay on average 5 months, in essence we may not receive any subsidy for our patients for eight months – impacting upon day to day services the Leukaemia Foundation provides.
- ◆ Increases in the PATS subsidy would allow more of our funds to be channelled into increasing other services to patients.

Conclusion

The Leukaemia Foundation would like to see the Patient Assisted Travel Scheme reviewed to reflect the needs of long term patients requiring accommodation in Perth.

Documentation needs to be simplified and based in the city – where patients can easily access all required information. Authorisation to sign claim forms is currently limited to the specialist, this should be extended to clinical nurses to make completion of documentation easier.

Discrepancies between individual PATS clerks and staff at McKesson Asia Pacific are a cause for much distress with patients and staff who administer accommodation payments. The inconsistencies between different regional pats clerks and also between clerks in the same office, causes general dissatisfaction and at times distress, with patients trying to access what they are rightfully entitled to.

Payment to not for profit organisations, such as ours requires timely interventions. Payments also need to reflect the true cost of providing accommodation.

Non health care card holders are extremely disadvantaged, increasing the out of pocket expenses of being in Perth for treatment.

Finally the Leukaemia Foundation highly recommends that all patients be able to have a carer provided for during treatment and recovery. The psychological impact of being alone during treatment is high; financially providing assistance to allow carers to be present would decrease the patient's potential anxiety, depression and isolation.