



I am writing to outline the response of the Oncology Social Work Australia (OSWA) WA Branch to **the parliamentary inquiry into the Patient Assisted Travel Scheme**. OSWA is a national body of social workers working with cancer patients in various health organisations in both metropolitan and rural settings. Working with PATS is part of our core business for rural patients. We address the terms of reference below, however the main issues are:

- Inconsistencies between PATS offices in terms of decisions, procedures, and clerk roles.
- Subsidies do not reflect the high cost of living in Perth/WA and there is a lack of affordable accommodation options close to treating hospitals.
- Medical specialist's clinical decisions that patients receive treatment in Perth and length of stay required are being challenged by PATS clerks without specific medical knowledge about the patient or their illness.
- Time limits to accommodation funding are being decided irrespective of the prescribed treatment duration.
- Need for Perth hospital based PATS liaison clerks
- Confusing and sometimes lengthy administration processes, particularly in the case of retrospective claims which leave patients out of pocket.

#### **How adequately PATS delivers assistance to regional people accessing specialist medical care**

Our members find that the adequacy of assistance delivered varies according to the location of the patient and the PATS office they deal with. Decisions, procedures and the duties of the PATS clerks have been inconsistent and guidelines on the role of the PATS clerk are unclear and open to interpretation.

#### **The level of funding applied to the transport and accommodation subsidies provided**

The cost of living in Perth, including accommodation, is generally high. \$60 for a single person or \$75 for 2 people does not go far for many accommodation options in Perth, especially short stay, furnished accommodation located close to treating hospitals (Cancer patients can become acutely unwell very rapidly, hence the need for proximity). Rural patients are financially disadvantaged when they are required to remain in Perth for sometimes very long periods of time for treatment. In addition to travel/accommodation costs, they also continue to have housing costs associated with their usual home. Our suggestion would be to adjust the subsidies in line with inflation and rising costs of living.

Accommodation options that are completely covered by PATS (for example Cancer Council & Leukaemia Foundation accommodation) are often fully booked weeks in advance, thus patients

requiring emergency or last minute accommodation are at a disadvantage. Other low cost accommodation facilities are also frequently booked out and the quality of some of these can be very poor and unsafe. Cancer patients generally suffer a weakened immune system due to the treatment and are more susceptible to infection which can be life threatening, thus requiring clean accommodation.

The fuel subsidy rate per kilometre was also set some time ago when fuel prices were considerably cheaper, thus consideration of increasing this subsidy in line with rising costs of living would also be beneficial for financially struggling families.

### **Eligibility for PATS funding**

As mentioned earlier, decisions and assistance provided varies according to the location of the PATS office, which includes approving eligibility. Sometimes the need for treatment in Perth rather than regional centres is questioned by non medical PATS clerks, despite medical specialists' signed documentation indicating so. On regular occasions, medical specialists have been asked to write separate letters providing explanation why patients need to receive treatment in Perth, which is not only time consuming but also questioning their medical judgement. For example whilst some chemotherapy can be given in some regional hospitals, this is dependent on a number of factors including the patient's medical comorbidities, the type of cancer and the type of chemotherapy required. It is not simply determined by geographical location and nearest proximity.

Six month time limits have also been applied to PATS funding when in fact patients may need to remain in Perth for up to 12 months or longer for treatment, particularly patients with some Haematological cancers. Whilst treatment, appointments and blood tests are frequent, they are not every day. However the risk of sudden acute deterioration, loss of blood products and possible death is quite high that the medical specialists require patients to remain in Perth over this time in order to be close to a tertiary hospital. Setting arbitrary time limits can cause additional stress for families who are worried about where to stay and how to afford it after this time. These patients are inappropriately penalised for having conditions requiring longer treatment, thus eligibility for PATS should directly correlate with the length of stay in Perth that the doctor has medically prescribed. Furthermore, it is difficult for doctors to set an end date for cancer treatment as they know that many factors (medical and systemic) can cause this to change.

As social workers, we are aware that appointments with allied health members are not included. We would strongly advocate that seeing various members of the allied health team is equally important for patient's physical functioning, maintaining independence, social and emotional well being and general quality of life.

### **The administration process**

The PATS administration process with various forms and sequence of coordination can be quite confusing for some patients, especially those with language, cognitive or mental health difficulties. The explanation of PATS provided to patients (both verbal and written) varies according to PATS areas thus some patients come to Perth unaware of PATS and its processes. Many patients are first diagnosed with cancers on emergency hospital admissions thus miss out on the opportunity for guidance and contact with PATS clerks before coming to Perth. Explaining and assisting with this

initial process is quite time consuming thus having dedicated PATS liaison clerks at Perth hospitals would make this process smoother and be able to offer clear, consistent, expert information. Furthermore the South West PATS area admittedly has a different application process, thus further confusing the situation. Streamlined, simplified processes are required with sufficient written information provided and widely advertised to rural patients before and after they come to Perth for treatment.

Retrospective claims can be challenging and financially draining to rural patients, for example when attending a Perth hospital urgently on the advice of their GP or medical specialist, without having time to make contact with their PATS office. Time frames for reimbursement, for travel or accommodation costs, again vary according to the PATS area ranging from a couple of weeks to a couple of months. The longer patients wait the greater the risk of financial strain, which potentially affects treatment adherence.

#### **Whether there is consideration of exceptional circumstances**

Some patients live transient life styles moving between regional towns for cultural, financial or other reasons. Our members have come across some situations where PATS offices have refused to provide funding for the patient, believing that the patient does not come under their catchment area. The case has been 'handballed' from office to office with no one willing to provide funding. Despite which catchment area the patient is from, they are still clearly a rural patient and thus entitled to PATS funding.

Another issue that currently lacks consideration is capacity for changing escorts, particularly when patients and escorts are required to remain in Perth for an extended period of time. The social, financial and emotional impact of remaining in Perth for a number of months affects both patients and escorts. Escorts are often required to travel between home and Perth to return to work, to continue caring for dependants, to attend to their affairs at home etc. In one complex example a patient's husband was initially her escort, then after some time returned home and the patient's daughter came to Perth. Under the current system, her transport was not funded. The daughter was pregnant at the time and also brought her dependant young child (children are also not funded under the current system). The daughter remained in Perth for a few months as the escort and subsequently had her baby and all obstetric care in Perth. The baby also had it's own medical conditions and spent some time at Princess Margaret Hospital. When the daughter/escort wished to return home, the cost of transport was again not funded despite her baby also having medical conditions requiring specialist treatment in Perth. In this case the social worker tried to advocate on her behalf with the PATS office but to no avail.

#### **Any incidental matter**

In some cases, for example a patient within the Peel PATS area living greater than 70km from Perth, approval and accommodation funding did not include nights that the patient was admitted to hospital. The impact of this is that accommodation booked in advance and unexpectedly not used (i.e. unexpected hospital admissions for infections or other complications), incurs a fee for the patient that will not be covered by PATS. It also delays discharging patients from hospital as we wait until the patient is medically ready for discharge before even sourcing accommodation, so as to

avoid paying unused accommodation fees, then finding available accommodation can often take a few days.

PATS offices vary when it comes to paying for accommodation directly via purchase orders, or getting the patient to pay upfront and reimbursing them. Some PATS offices have arrangements to pay directly with a number of commonly used accommodation facilities close to hospitals, whilst others, for example Albany PATS, have restricted this to a few facilities. Many patients do not have access to immediate funds to pay for accommodation upfront and can not afford to wait up to a couple of months for a reimbursement. This narrows down their accommodation options significantly, particularly when short notice is given. This often delays patients discharge from hospital as there is nowhere to discharge them to in Perth.

With the new Fiona Stanley Hospital being built in the southern Perth suburbs, our members are concerned regarding the lack of availability of accommodation-affordable or otherwise-in the surrounding area. The Cancer Council's accommodation facilities are located close to inner city hospitals, but to our knowledge there is no Cancer Council accommodation planned close to Fiona Stanley, which will also house another cancer centre. Government funding to assist with this would be ideal. In addition, Jewell House has provided inner city accommodation completely covered by PATS funding but is scheduled for closure at the end of the year. Without opening alternative PATS covered accommodation, we are concerned at the financial impact this will have on patients and the delays in hospital discharge and potential delays on treatment. This is often a source of great stress for patients who fear this will also impact on their chance of survival.

With regards to indigenous patients, indigenous specific accommodation is unique in terms of the additional formal and informal support it provides. There is a general shortage of this accommodation in Perth and again in the southern suburbs close to Fiona Stanley Hospital. Country Health Connection is also a service that supports rural indigenous patients with accommodation, transport and PATS coordination, however this service is quite stretched. They previously provided a 'meet and greet' service to rural indigenous patients arriving in Perth which helped these patients to familiarise themselves with their surroundings and travel to/from the hospital. They unfortunately no longer have the resources to do so.

Thank you for your consideration of the issues raised in this submission. If you require further clarification, feel free to contact us.

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