

Palliative Care Australia

Submission to:

SENATE COMMUNITY AFFAIRS COMMITTEE

**INQUIRY INTO OPERATION AND EFFECTIVENESS OF
PATIENT ASSISTED TRAVEL SCHEMES**



**Palliative
Care
Australia**

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EXECUTIVE SUMMARY

Palliative Care Australia is pleased to provide a submission to the Senate Community Affairs Committee *Inquiry into operation and effectiveness of Patient Assisted Travel Schemes (PATS)*. In making this submission, PCA has narrowed its focus to the specific needs of people receiving palliative care, noting there are many other issues with the PATS systems outside this domain. Palliative Care Australia's submission should be read in conjunction with other more widely focussed submissions.

For people receiving palliative care in rural and remote areas, PATS are of vital importance. The diagnosis of a terminal illness is a time of extraordinary financial and emotional stress. Optimum quality care for terminally ill people, their families and caregivers, can often involve active treatment for the illness to control symptoms and maximise quality of life, thus necessitating frequent health professional contact.

- . The key issues for people receiving palliative care and their families and caregivers are:
 - **distance** – distance requirements for eligibility do not include a phase-in point where patients may receive a proportion of the full subsidy if they are located near the cut-off point
 - **allied health** – palliative patients require access to allied health expertise for the control of symptoms – when symptoms are controlled, patients can be cared for in a home environment - this should be covered under by PATS
 - **bereavement** – access to bereavement support following the death of the patient should be covered by PATS
 - **escorts** – even if a palliative patient is physically able to travel independently, an escort should be funded on the basis of emotional support or to facilitate culturally specific decision making if required
 - **administrative arrangements** – access to general practitioners to authorise forms can be problematic in rural and regional areas and arrangements for patients who travel regularly are needed to streamline the approval process
 - **cost** – the cost of the PATS subsidy is insufficient to contribute in a meaningful way to the real cost of travel and accommodation
 - **repatriation** – the repatriation of a body should be covered if the patient travelled to the treatment centre under PATS.

RECOMMENDATIONS

2.2 - PATS and Distance

2.2.1 - Recommendation: PCA recommends PATS guidelines for subsidy for distance travelled be nationally consistent and operate on two levels: 50km – 100km, and 100km + with differing subsidy rates.

2.3 - PATS and Allied Health

2.3.1 - Recommendation: PCA recommends PATS guidelines be reviewed to include consultations with allied health professionals.

2.3.2 - Recommendation: PCA recommends PATS continue to apply to families and caregivers for three months post death should counselling and bereavement support be required.

2.4 - PATS and Escorts

2.4.1 - Recommendation: PCA recommends all PATS guidelines be amended to clearly include “emotional support” or the “facilitation of culturally specific decision making” in addition to physical support to determine eligibility for an escort for patients receiving palliative care.

2.5 - PATS and Administrative Arrangements

2.5.1 - Recommendation: PCA recommends PATS investigate options for other registered health professionals to validate PATS eligibility and to authorise PATS forms, for example community nurses in consultation with a general practitioner.

2.5.2 - Recommendation: PCA recommends arrangements be put in place for patients who frequently travel for medical treatment so there is no need to complete the administrative process each time.

2.5.3 - Recommendation: PCA recommends consideration be given to alternative reimbursement systems to reduce the impact of out-of-pocket expenditure. A national administrative system, perhaps aligned with Medicare would enable a more efficient reimbursement process.

2.5.4 – Recommendation: PCA recommends nationally consistent eligibility and reimbursement schedules for all PATS schemes.

2.6 - PATS and Cost

2.6.1 - Recommendation: PCA recommends subsidy levels for travel and accommodation be reviewed to more accurately reflect the cost to palliative patients and their families. There should be no cost difference to the individual of attending a healthcare service, whether metropolitan or regional.

2.6.2 - Recommendation: PCA recommends consideration be given to a 100% reimbursement for eligible expenses for palliative patients in the final terminal phase¹ of an illness.

¹ The final terminal phase of an illness is defined as 4 months.

2.6.3 - Recommendation: PCA recommends that the over reliance on not-for-profit community groups to provide accommodation be addressed. This can be achieved through financial support to enable these services to meet all the accommodation needs associated with major metropolitan or regional hospitals beyond a cancer diagnosis OR through funding for the establishment of accommodation infrastructure at hospitals.

2.6.4 - Recommendation: PCA recommends government negotiates special accommodation rates at accommodation venues close to all major metropolitan and regional hospitals. This would be similar to the “government/corporate rate” often offered by hotels to government employees.

2.6.5 - Recommendation: PCA recommends exploration of innovative methods for access to medical care that do not require attendance at a tertiary hospital. Advances in information technology to enable remote consultations through videoconferencing have potential to increase access to specialist expertise (such as pain management) and other services such as teleradiography and telepsychiatry.

2.6.6 - Recommendation: PCA Recommends expansion of the MSOAP (Medical Specialist Outreach Assistance Program) to provide for direct care to rural and regional patients.

2.7 - PATS and Repatriation

2.7.1 - Recommendation: PCA recommends PATS guidelines be altered to include the repatriation of a body should the patient die whilst receiving treatment.

1 – PCA AND PALLIATIVE CARE

1.1 PALLIATIVE CARE AUSTRALIA

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality palliative care available for all. Palliative care should be: timely, needs-based and evidence-based.

Palliative Care Australia is an incorporated body whose members are the eight state and territory palliative care associations and the Australian and New Zealand Society of Palliative Medicine. The membership of these associations includes palliative care service providers, clinicians, academics, consumers and members of the general community.

Palliative Care Australia was formed in 1990 to address national palliative care issues, represent the area to the Federal Government and national media, and to act for the sector when dealing with other national peak bodies and professional organisations.

Palliative Care Australia works in collaboration with the Australian Government Department of Health and Ageing to implement the National Palliative Care Strategy and to raise awareness of palliative care, improve the understanding and availability of services across Australia, and encourage discussion to support improved knowledge networks.

1.2 PALLIATIVE CARE

Palliative care is specialised care and support provided to people with an active, progressive and advanced disease or illness, for whom there is little or no prospect of cure. Palliative care is holistic care, focussing on quality of life and helping people live well.

Palliative care addresses the physical needs of the patient, including prevention and relief of suffering by means of early identification and assessment of pain and other problems. As a holistic approach, it also addresses the emotional, social, cultural and spiritual needs of the patient, as well as those of their family and caregivers.

Palliative care is delivered by a multidisciplinary team which may include: doctors (specialists and GPs), nurses, physiotherapists, occupational therapists, dieticians, social workers, counsellors, chaplains and volunteers.

Palliative care affirms life and regards dying as a normal process. Palliative care is intended neither to hasten, nor postpone death. Rather, it is an integration of the physical, emotional and social aspects of care and offers a support system to help patients live as actively as possible until death. Importantly, palliative care offers a vital support system to help the family cope during the patient's illness and in their own bereavement.

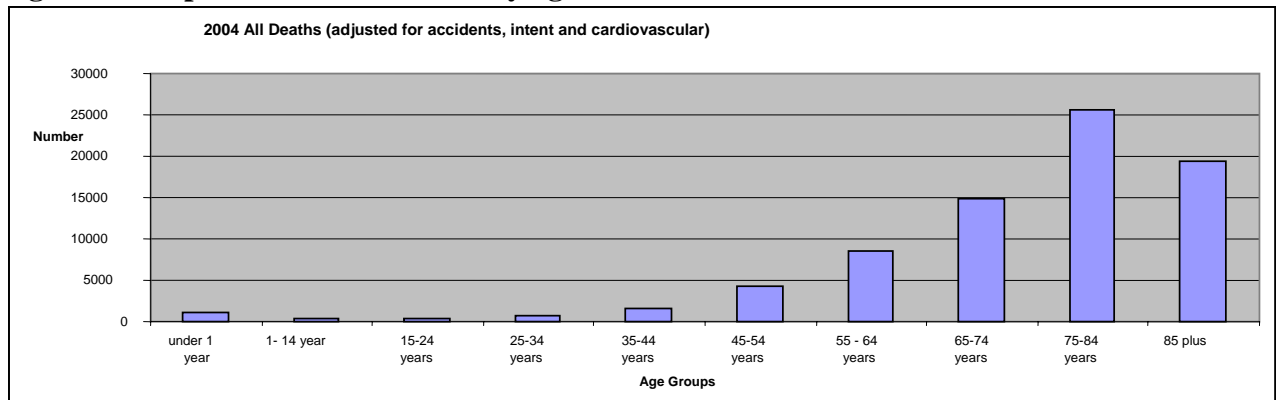
1.3 CAUSES OF DEATH IN AUSTRALIA

In 2004, 132,501 Australians died.² Of these, approximately 77,000 were expected deaths (55,608 deaths were unexpected – 8,081 attributed to accidents or intentional harm, and 47,527 attributed to cardiovascular illness³) Death events that are expected will have a palliative phase.

² *Causes of Death Australia 2004*, Australian Bureau of Statistics.

³ Note that not all cardiovascular deaths are sudden deaths. This figure is excluded from “expected deaths” to ensure a conservative estimate of expected deaths.

Figure 1 – Expected Deaths in 2004 by age



1.4 FINANCIAL PRESSURE

Financial pressures in particular, exacerbate the physical and emotional hardships of terminal illness and significantly increase the risk of adverse impacts for patients, their families and caregivers – before and after death. Whether employed or not, terminal illness causes financial pressures. Those who are employed will experience reduced income and significantly increased health costs. Those who are unemployed or beyond working age will have to meet increased health costs from the same base income.

An employed person diagnosed with a terminal illness will, at some stage in the illness trajectory, be unable to continue paid employment. In the best case scenario, they may have paid entitlements (sick leave, annual leave and other leave payments) to cover some or all of their terminal phase. This will be dependent on the nature of their illness and the length and type of employment (part-time, casual, full-time, or self employed).

Where the patient is of working age and not employed prior to the diagnosis of a terminal illness, it is likely they will have limited or no savings to cover their living and care costs during their terminal phase. Such persons may be on some form of government concession (i.e. unemployment benefit, sickness benefit) prior to their terminal phase or they may simply not be in employment, be between jobs and/or supported financially by their partner.

People diagnosed with a terminal illness become dependent on others for their care as the illness progresses. Often, care is undertaken by a partner or family member who usually needs to leave the workforce in order to provide necessary care. In many cases, household incomes go from two incomes to no income. Paid private care in the home is often unaffordable and in some cases, undesirable. Research shows that one in four workers with caring responsibilities have reduced their hours of work because of the high cost of alternative care.⁴

When a patient enters the terminal phase of an illness, they may have been living with the illness and receiving palliative care for a period of months or even years. Consequently, they will have lived with reduced income for a lengthy period of time. Costs of the illness will have accumulated, particularly if a partner has left the workforce to provide care, and the final, intensive terminal phase is likely to be financially crippling.

Palliative patients often require intensive access to specialist skills to control symptoms and maximise quality of life. At this time of financial and emotional stress, patient assistance travel schemes are of central importance to patients and families in rural and remote areas.

⁴ *Interim Report, 2006, Taskforce on Care Costs, p. 7.* Furthermore, after leaving the workforce, 52 percent of unemployed carers feel that their skills have been reduced whilst off work, and 49 percent have reduced confidence in their ability to return to work.

2 – PALLIATIVE CARE IN RURAL AND REMOTE AREAS

2.1 EQUITY OF ACCESS

Palliative Care Australia's vision is quality palliative care available to all based on clinical need and regardless of location, age, income, diagnosis, prognosis, and social or cultural background. This is supported by the *Standards for Providing Quality Care for All Australians*.⁵

Ensuring access for all Australians to high quality needs based palliative care is also a key aim of the Australian Government National Palliative Care Strategy.⁶ Appropriate care is of critical importance in supporting and maintaining quality of life for people who are dying. It is also crucial in enabling families to come to terms with the death and to continue functioning as part of community and society.

The manner in which a patient dies affects the bereavement process of the family and caregivers. If a patient is able to access medical and allied health care to control symptoms and maximise quality of life, the family is under comparably less stress than if a patient is unable to access medical treatment and suffers in the time until death.

The context of the health system with which patients receiving palliative care interact is one where health services have increasingly been centralised in major regional or metropolitan areas. This reduction of hospital services in rural and regional areas has led to a transfer of costs from the public purse to the private rural and regional resident. A significant amount of the direct and indirect costs are borne by patients in rural and regional Australia which are partially subsidised by state and territory travel assistance schemes.⁷

Equity of access cannot be guaranteed until people in rural and regional areas receive sufficient financial and administrative support to achieve parity with people in metropolitan areas.

Palliative patients receive active treatment for their illnesses to control symptoms and maximise quality of life. Broadly speaking, palliative patients require access to a range of health professionals to meet their needs:

- Physical – palliative patients, particularly in the terminal phase of an illness, often experience rapidly fluctuating symptoms, such as chronic nausea, pain or breathlessness. Access to specialist medical expertise for difficult to control symptoms, and in some cases in-patient care, is essential.

Patients with such illnesses as cancer will often continue to receive regular active treatment such as radiotherapy to control pain and other symptoms and improve quality of life. Allied health expertise is often essential in controlling symptoms and maximising quality of life, for example physiotherapy, speech therapy, occupational therapy or dietitian advice.

- Psychosocial (emotional, spiritual, cultural, social) – palliative patients and their families and caregivers have a range of emotional needs relating to fears about

⁵ Palliative Care Australia, 2005. *Standards for Providing Quality Palliative Care for All Australians*, Palliative Care Australia, Canberra, p. 36.

⁶ *National Palliative Care Strategy*, 2000, Commonwealth Department of Health and Aged Care, Canberra.

⁷ Webber, K.M. 2005. *General Practice Hospital Integration in Rural and Remote Australia: Summary of Findings*, Australian Rural Health Education Network.

prognosis, coping abilities, grief and bereavement.⁸ It is often essential for palliative patients and their families to receive counselling and psychological support.

The issues listed below serve as barriers to people living in rural and remote areas accessing quality palliative care.

2.2 PATS AND DISTANCE

The PATS arrangements in each state and territory set a definite distance requirement for eligibility. This means, for example, a patient in Western Australia who must travel 99 kilometres does not receive assistance but a patient who must travel 101 kilometres does.

Scenario 1: Phil is an aged pensioner and has a brain tumour which has grown to the extent his local general practitioner and community nurse are unable to control his symptoms. He is experiencing difficulty to manage seizures as well as uncontrolled nausea and vomiting. Phil and his wife Pat live 80km away from a major tertiary hospital. Phil needs regular hospitalisation to keep his symptoms under control. Because Phil lives only 80km from the hospital he is not eligible for PATS in the state in which he lives. The financial burden of covering the cost of car travel and accommodation for Pat when Phil is admitted overnight has meant Phil and Pat have needed to borrow from family and friends and have incurred significant debt.

2.2.1 - Recommendation: PCA recommends PATS guidelines for subsidy for distance travelled be nationally consistent and operate on two levels: 50km – 100km, and 100km + with differing subsidy rates.

2.3 PATS AND ALLIED HEALTH

Palliative patients often require access to a range of allied health professionals such as physiotherapists or speech therapists, for the control of symptoms to maximise quality of life. Palliative patients admitted to hospital for control of symptoms may be referred to outpatient services upon discharge. Hospitals are required to provide these outpatient services free of charge. However, access to these services requires patients to travel again from rural and remote areas.⁹

Furthermore, the diagnosis of a terminal illness is a time of extraordinary stress as families come to terms with their grief and subsequent bereavement. The *Standards for palliative care* specify that “formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services”.¹⁰ Access to counselling and psychological support is often necessary to allow patients and their families to come to terms with the diagnosis. This expertise is often unavailable in rural and remote areas.

The PATS arrangements are centred around specialist care and rarely provide for access to allied health services, even if this is imperative to the control of symptoms. This makes it less likely rural and regional patients will travel to receive an outpatient service provided by a hospital or to seek out other allied health professional support in larger regional or metropolitan areas.

⁸ Hiramaneek, N. & McAvoy, B. 2005. “Meeting the needs of patients with cancer”, *Australian Family Physician*, Vol. 34, No. 5, May, pp. 365-367.

⁹ Webber, K.M. 2005. *General Practice Hospital Integration in Rural and Remote Australia: Summary of Findings*, Australian Rural Health Education Network.

¹⁰ Palliative Care Australia, 2005. *Standards for Providing Quality Palliative Care for All Australians*, Palliative Care Australia, Canberra, p. 33.

2.3.1 - Recommendation: PCA recommends PATS guidelines be reviewed to include consultations with allied health professionals.

2.3.2 - Recommendation: PCA recommends PATS continue to apply to families and caregivers for three months post death should counselling and bereavement support be required.

2.4 PATS AND ESCORTS

Anecdotal evidence suggests guidelines in relation to escorts are variously applied. In a palliative situation, patients, families and caregivers are under extraordinary stress.

Scenario 2: Ruth is 54 and has secondary breast cancer for which she receives palliative radiation. She lives in the Northern Territory and must travel to Adelaide to receive the treatment. This often takes up to two weeks each time. Because Ruth is physically able to support herself, her request for an escort on psychological grounds is denied by the PATS administrator.¹¹

Scenario 3: Jan and John have a son Jack with terminal leukaemia. Because Jack is under 18, PATS will cover escort costs for Jan to travel with Jack to receive regular platelet transfusions. However, the emotional strain on Jan is enormous and she requires the support of her husband when staying with Jack while he has his treatments in a major tertiary hospital. PATS will not cover the cost for John to travel as an escort.

The diagnosis of a terminal illness and subsequent treatment can be emotionally burdensome and palliative patients need the support of family and friends. Emotional needs are exacerbated for rural and regional patients by the distance from family and friends.¹²

2.4.1 - Recommendation: PCA recommends all PATS guidelines be amended to clearly include “emotional support” or the “facilitation of culturally specific decision making” in addition to physical support to determine eligibility for an escort for patients receiving palliative care.

2.5 PATS AND ADMINISTRATIVE ARRANGEMENTS

In most cases, the general practitioner is the gatekeeper for access to PATS. Applications for PATS assistance must be signed by a general practitioner. This arrangement does not take into account a number of difficulties faced by rural and regional patients.

In some rural and remote areas, access to a general practitioner is problematic and patients can be forced to wait for long periods.

Scenario 4: Bill lives in a remote community with a small community hospital. He needs to travel to a regional centre to receive palliative chemotherapy. In the absence of a general practitioner, patients wishing to access PATS must have the form signed by a doctor at the hospital. Bill can wait up to eight hours for a doctor to sign each PATS form. On occasion, nursing staff may authorise the form, even though this is not permitted under PATS arrangements.

¹¹ This case subsequently came to the attention of the relevant Minister for Health and Ruth’s husband was funded to travel with her.

¹² Webber, K.M. 2005, *General Practice Hospital Integration in Rural and Remote Australia: Summary of Findings*, Australian Rural Health Education Network.

Scenario 3 continued: Jack requires platelet transfusions twice per week and occasionally in emergency circumstances to control symptoms. The family lives in regional South Australia and platelet transfusions are administered at a tertiary hospital in Adelaide. The current PATS arrangements mean Jan and John have to complete a new application for each journey to Adelaide.

2.5.1 - Recommendation: PCA recommends PATS investigate options for other registered health professionals to validate PATS eligibility and to authorise PATS forms, for example community nurses in consultation with a general practitioner.

2.5.2 - Recommendation: PCA recommends arrangements be put in place for patients who frequently travel for medical treatment so there is no need to complete the administrative process each time.

2.5.3 - Recommendation: PCA recommends consideration be given to alternative reimbursement systems to reduce the impact of out-of-pocket expenditure. A national administrative system, perhaps aligned with Medicare would enable a more efficient reimbursement process.

2.5.4 – Recommendation: PCA recommends nationally consistent eligibility and reimbursement schedules for all PATS schemes.

2.6 PATS AND COST

The PATS arrangements are determined on the basis of a subsidy rather than reimbursement of the actual cost of the travel. Evidence suggests the PATS subsidies are insufficient and the need to travel for medical attention leaves many families in debt.

Scenario 5: Ken is a pensioner living in Tenant Creek, 500km from Alice Springs. To receive palliative chemotherapy, he needs to travel to Alice Springs. He must drive to Alice Springs and spend a minimum of four days whilst receiving the chemotherapy and other follow up treatments. The current PATS arrangements mean Ken cannot receive any payments upfront, he must first incur the expenses for petrol (\$200 for a round trip) and accommodation from his small pension. Being a major tourist destination, the cost of accommodation in Alice Springs is high. The PATS contribution of \$30 per night leaves Ken more than \$100 per night out of pocket. On occasion, when Ken is unable to meet the travel and accommodation costs, the hospital will admit Ken as an inpatient (at a cost to the hospital of between \$600 and \$800 per day) to ensure he can receive his treatment.

Patients who require air travel have their airfares paid directly by the administering authority. However, patients who need to travel by car must first incur the cost before being reimbursed a portion of the cost of travel.

Accommodation subsidies, ranging from \$30 to \$33 per night (depending on the state/territory administering the PATS) are insufficient for the actual cost of accommodation unless patients and escorts are able to access special hospital accommodation or other community provided housing. Anecdotal evidence suggests palliative patients and their escorts who need to travel for care incur large amounts of debt.

Scenario 3 continued: Jack requires platelet transfusions twice per week, administered at a tertiary hospital in Adelaide. Faced with the prohibitive financial costs of these regular trips, the administrative burden and the inadequate reimbursement from the PATS, the hospital has arranged for the family to stay in a house funded by a not-for-profit community group for patients with cancer and their families.

It is the case that not-for-profit community groups often fill the gap when PATS does not provide adequate assistance to cover the cost of accommodation. However, the majority of this type of accommodation is reserved for patients with cancer and there are lengthy waiting lists. Research reveals more than half of children referred for palliative care have a diagnosis other than cancer.¹³ Families and caregivers have little choice but to incur large debts which add to the burden of grief and bereavement.

Furthermore, studies show household incomes in rural and remote areas are generally lower than urban areas. There is also a direct association between socio-economic disadvantage and distance from urban centres. This suggests those least able to cope with the expense are being required to pay, contributing to significant financial and emotional stress.¹⁴

2.6.1 - Recommendation: PCA recommends subsidy levels for travel and accommodation be reviewed to more accurately reflect the cost to palliative patients and their families. There should be no cost difference to the individual of attending a healthcare service, whether metropolitan or regional.

2.6.2 - Recommendation: PCA recommends consideration be given to a 100% reimbursement for eligible expenses for palliative patients in the final terminal phase of an illness.

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2.6.6 - Recommendation: PCA Recommends expansion of the MSOAP (Medical Specialist Outreach Assistance Program) to provide for direct care to rural and regional patients.

¹³ Department of Health and Ageing. 2004. *Paediatric Palliative Care Service Review*, Commonwealth of Australia, Canberra.

¹⁴ Webber, K.M. 2005. *General Practice Hospital Integration in Rural and Remote Australia: Summary of Findings*, Australian Rural Health Education Network

2.7 PATS AND REPATRIATION

Patients from rural and remote areas are sometimes transferred to major tertiary hospitals in the final terminal phase if they are experiencing symptoms which cannot be controlled in a home or community setting. If the patient dies while in hospital, PATS will not provide any contribution towards the cost of repatriating the body to the patient's home town. The cost of arranging for transportation back to the patient's home town, in addition to the cost the family will already have incurred in terms of travel and accommodation and other incidentals not covered by PATS, combined with the average cost of a funeral (approximately \$6,000 - \$8,000), leaves many bereaved families in significant debt.

2.7.1 - Recommendation: PCA recommends PATS guidelines be altered to include the repatriation of a body should the patient die whilst receiving treatment.

3 – CONCLUSION

Travel and accommodation assistance is crucial for patients and their families and caregivers in rural and regional areas when they need to access medical services not available in their own communities. Palliative care should be available to all based on clinical need and regardless of location, age, income, diagnosis, prognosis, and social or cultural background.

The PATS systems must ensure equitable access, based on need, to the range of health services required by patients, regardless of geographical location and should not be limited solely to specialist services.

There are a number of areas in which the current PATS arrangements could be improved. The recommendations for improvement would be greatly enhanced if guidelines were harmonised between jurisdictions.



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