



**Palliative
Care
Australia**

**Submission to the Queensland Parliament
Health and Community Services Committee**

Palliative care services and home and community care services Inquiry

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Introduction

Palliative Care Australia (PCA) is the peak national organisation representing all state and territory palliative care organisations, the Australian and New Zealand Society of Palliative Medicine, and the interests and aspirations of all who share the ideal of quality care at the end of life.

Our vision is to achieve quality care at the end of life for all. PCA's mission is to influence, foster and promote the delivery of quality care at the end of life for all. PCA advocates for equitable, needs based delivery of quality care at the end of life through promotion of the principles of palliative care; development of evidence and needs based service provision models; workforce capacity building; awareness and community capacity building; appropriate funding and resourcing. Palliative care has been defined by the World Health Organization¹ (WHO) as:

An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

When an illness cannot be cured, the focus of care changes to supporting and assisting patients to have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms, such as pain or nausea, as well as helping with emotional, spiritual and social needs. A person receiving palliative care will have an active, progressive and far advanced disease, with little or no prospect of cure. The aim of palliative care is to achieve the best possible quality of life for the individual patient, their carers and families.

¹World Health Organization, *WHO definition of Palliative Care*, 2008. <http://www.who.int/cancer/palliative/definition/en/>

PCA welcomes the opportunity to address the Queensland Parliamentary Inquiry terms of reference as they relate to palliative care. PCA also welcomes any feedback the Inquiry process may take including opportunities to address the Inquiry in person.

Queensland Parliamentary Terms of Reference

1. The capacity and future needs of palliative care services (including children and adolescents palliative care)

There are a number of factors that contribute to the capacity to provide optimal palliative care in Australia. Many of them interact and overlap, impacting on our ability to provide accessible, effective and appropriate quality palliative and end of life care. They include:

Access

Access along with equity is one of the fundamental issues impacting on the capacity of palliative care in Australia to be effective in addressing the needs of people with life threatening conditions. Although each of the following are in themselves important issues, collectively they become highly significant and should be taken on board and dealt with concurrently in planning effective strategies for end of life and palliative care services:

Care all of the time - Care round-the-clock is something that is vital for patients and families facing issues at the end of life. The unpredictability of the time when care may be needed is a feature of this population and if even basic levels of care (with consultancy back-up from identified specialist palliative care services) is unavailable these patients will be forced to call for an ambulance and go to the closest Emergency Department.

Care in all places - Community Care is something that state governments have increasingly become involved with in an effort to minimise overuse of the costly hospital system from Emergency Departments to various acute care wards. This is a crucial issue for an end of life population (last 12 months of life) needing palliative care, as we know that over 75% of these patients would prefer to be cared for at home. Many of these patients currently attend Emergency Departments and are admitted to acute care wards and the home death rate is low in Qld. (15-28%).

Geographic distances in Australia influence how we live, the number, the type, the access to and quality of services and other resources. The more rural and remote areas of the country compound the issue of access to both specialist and generalist palliative care providers, including general practitioners (GPs).

A person's awareness and level of health literacy in relation to death and dying contributes to the level of access, as does socioeconomic status, ethnicity and cultural background. An awareness and heightened levels of health literacy about death and dying promotes acceptance and uptake of advance care plans and promotes the notion of choice,

particularly as to where a person may wish to die and the type of care they would choose to receive.

The number of health care practitioners and other carers trained in, or having the right skill set, to provide the right type of care, in the right place, at the right time, are contributing factors to quality care, as is where these numbers of individuals are located. The challenges in meeting the future development needs of the specialist palliative care and wider healthcare workforce to provide high quality care to people approaching the end of life can be considered to be a subset of the broader challenges of developing a sustainable, skilled and adaptable workforce to meet the health needs of the Australian community.

The number of educational institutions providing courses in palliative care, their quality and the number of students taking up courses.

High quality information is a key lever for change. Without relevant, timely information and data it is not possible to undertake informed decision making about service delivery, assess current practice or indeed enable assessment of the impact of improvement efforts.

Cultural competency. A key determinant of the ability to access services is the influence of culture and ethnicity on end of life care, both from the perspective of consumer and carer choices, and the cultural competencies of health care providers.

Workforce

This is an issue for urgent attention by all governments in Australia. It includes a range of factors, each of which contributes to our capacity or incapacity to provide optimal, quality palliative and end of life care and impacts on current and future need of palliative care services:

An ageing health care workforce is a problem linked to the overall ageing of the Australian population. There is an urgent need to look at replacement strategies to address the increasing numbers of retiring health care practitioners, particularly those working in the palliative and end of life care. This issue is exacerbated in rural and remote areas.

Recruitment, development and retention of workforce is a significant issue, particularly in regional, rural and remote areas. Working in rural and remote areas is seen as a less attractive option for many new graduates or for those with established practices in metropolitan areas. Some of the issues focus on concerns about supervision, access to continuing education and professional development, professional and social isolation, poor quality housing and educational opportunities for children.

Formal regionalisation of the specialist palliative care workforce by building capacity for them to provide telehealth, day clinics, and being available to provide advice to generalist service providers is vital. There needs to be sufficient numbers of highly trained specialist services to have doctors and nurses on-call around the clock for the primary care providers, due to the unique unpredictability of when this expert advice on palliative care may be

needed. To avoid burnout, sustainable regionalised specialist palliative care workforces need to be planned, trained and funded.

More education and training at undergraduate and postgraduate level is needed in end of life and palliative care. This must also include courses which prepare health practitioners for entry to practice and continuing professional development, as well as specialist training programs for all disciplines (nurses, doctors and allied health) in palliative care. Access to sufficient numbers of specialist training positions and educational programs is needed to meet the growing demand for quality end of life care. There is a need for a comprehensive workforce strategy in this regard, which embeds palliative care as a core part of the curriculum across all undergraduate, postgraduate and continuing education courses. A recurring theme for quality palliative care provision is access to ongoing training.

Upskilling and continuing education of the current healthcare workforce, in particular those working in the aged care sector, would assist capacity to provide appropriate and higher quality end of life care. Continuing professional development in palliative care requires flexible approaches to meet the needs of health practitioners in various practice contexts to promote accessibility and to enable ongoing learning. A knowledge-led culture that supports opportunities for health practitioners providing end of life care to engage in ongoing learning and continuous improvement is integral to quality end of life care.

An equitable distribution of the specialist and primary healthcare workforce is needed to meet the needs of people at the end of life. As mentioned above, having the right number of health care practitioners with the right training and skill set providing the right type of care in the right place at the right time, will contribute to the level and quality of care and enhance capacity. It is recognised that this will always be a problem for rural and remote areas, however formally regionalising the specialist workforce, embracing telehealth and use of day clinics and providing identified on-call specialist consultancy services with whom the primary care providers can develop an ongoing working relationship will make a significant contribution to the solution of problems associated with geography in Queensland.

Better rates of pay are needed as incentive to recruit and retain a skilled workforce. A low paid workforce is a contributing factor to reduced capacity to provide palliative and end of life care. This is particularly true in the aged care sector.

Cultural competence and culturally safe practice needs to be integrated into learning at all levels. Of particular importance is the need to effectively address the delivery of end of life care services to Indigenous and Culturally and Linguistically Diverse (CALD) communities, which requires a fundamental shift in the ability of the health workforce to meet their needs.

Funding

Sub-acute funding

The provision of high quality care at the end of life is not possible without adequate, appropriate, and equitable resourcing. Inadequate resourcing also fundamentally affects workforce distribution and this in turn affects the ability of patients and carers to gain access to a service, often resulting in suboptimal outcomes. Funding and other resources need to support flexible models of care rather than create barriers to them, which is what we currently see in end of life care in Australia. Funding is a critical issue for palliative care services in this country. The current inadequate and inequitable funding arrangements for palliative care have, and will continue to have, a significant impact on service provision and patient care if not addressed immediately.

The way palliative care funding is distributed has changed over time with noticeable inconsistencies across states and territories. In December 2008, the National Partnership Agreement on Hospital Health Workforce Reform allocated funding to palliative care services as part of a category of sub-acute services which includes rehabilitation, geriatric evaluation management, and psychogeriatric services.

In 2008-09, the Australian Government committed \$500 million for jurisdictions to expand health service provision levels by 5 per cent annually over the period 2009-13 and to address inequities in regional availability. However, there was no financial commitment required from the states and territories to increase sub-acute funding. Each jurisdiction could allocate the funding across the sub-acute sector as they determined based on local need.

With no standard template for reporting, not all jurisdictions have delineated spending between specialties and the sharp contrasts between jurisdictions are evident. Of its \$39,973 sub-acute funding, South Australia committed \$11,970 to palliative care. On the other hand, Queensland allocated none of the sub-acute funding to palliative care, but committed to undertake a review of the current palliative care service system in 2009-2010 from within existing state funding, and develop a strategic direction for palliative care. This service provision review has been undertaken, but not publicly released. Subsequently, the 2010 Federal Budget allocated \$1.62 billion to deliver 1,316 subacute care beds or bed equivalents, also to be allocated between sub-acute specialties by the different jurisdictions. There has yet to be public reporting of the allocation of these funds, but feedback from the sector does not indicate that there has been flow through to palliative care service provision.

We know that many more Australians would benefit from access to palliative care, yet it is clear that bundling funding allocations within the sub-acute category is not leading to improved service provision and access across the country. If such bundled allocations continue, whether or not in conjunction with Activity Based Funding, a significant level of

funding must be specifically allocated to palliative care (as a minimum) to ensure greater access to quality end of life care for Australians in need.

Funding Inconsistencies

Historically, palliative care service funding has been linked to cancer services. Modern cancer treatments have seen an increase in the symptom burden during the palliative phase. However, more people are now dying from end stage organ failure and dementia, and management of these disease trajectories are significantly more complex. It necessitates more coordination of multidisciplinary care and a rethink about funding and the way in which sub-acute funding is provided and used.

The historical cancer based funding model has not been reviewed and changed to meet these increased demands resulting in inequitable service provision for patients suffering from non-cancer related terminal conditions such as dementia, renal failure, heart failure, end stage respiratory disease and many other chronic diseases.

The funding and delivery mechanisms for acute and sub-acute inpatient care and community based services vary markedly throughout Australia. In areas where inpatient and community based services are delivered through different agencies or services, funding anomalies can significantly impede effective care. For instance, sub-acute inpatient funding may only cover the basic costs of the bed, and not any other services or treatments that may be required for the patient.

Aged care funding is structured on the assumption of 'stable' care requirements. If a resident becomes 'unstable' there is no provision for funding to provide necessary services, even where they could be most effectively delivered at the Residential Aged Care Facility (RACF). As a result, RACFs often have to transfer a resident to hospital to access necessary treatment.

Activity Based Funding

The implementation of Activity Based Funding (ABF) in hospital auspiced palliative care will begin across the Australian health system from 1 July 2013. Theoretically, ABF will enable funding models to better reflect the costs and resources involved in delivering palliative care and to place resources where they will deliver the best outcome for clients.

In comparison to ABF, the primary aim of Flexible Funding is to ensure that money can be assigned where and when it is needed in circumstances outside of prescribed boundaries defined by the ABF. These circumstances often arise in palliative care where for instance, if a person wishes to be cared for, eventually to die at home their palliative care requirements and quality of care are not compromised simply because their care needs fall outside of case-mix codes.

A potential fault with the ABF model is its lack of delineation between diagnoses. Some disease trajectories may require greater complexity of care at every phase (e.g. motor

neurone disease, patients with advanced cancer and spinal cord compression), others at specific phases. There is no current data to enable clear baselines to be established, so the impact of different diagnoses may be an important factor in costing. Even if not included initially, the system must be flexible to allow for changes to ensure adequate levels of resourcing.

The concept of the patient in palliative care is unique within the health system. In addition to the person with a terminal illness, palliative care treats and supports the family, carers, loved ones, and others. This care delivery to all related individuals, and inherent expansion of meaning of the concept of the term patient is integral to the philosophy of palliative care. It is essential that this expanded notion of a patient is recognised within the funding models. Given that the plans for ABF indicate a service event is between one patient and one health professional, it is essential that an expanded concept of patient be applied to palliative care. PCA understands that it is already the intention of the Independent Hospital Pricing Authority (IHPA) to treat bereavement services delivered to the carer/s and loved one/s of a deceased patient as a service event, this conceptual expansion may offer a mechanism to expand the overall concept of patient in palliative care delivery.

A further issue with ABF is the definition of a service event as being delivered by a clinician – defined as a medical, nursing or allied health practitioner. Palliative care is delivered by a multidisciplinary team that extends beyond this definition of clinician. Whether a pastoral carer providing spiritual support, a care worker assisting with showering, or a volunteer carer who still needs funding for training and coordination, the inclusion of these non-clinicians must be recognised within the costing model. All are integral to providing dignified end of life care.

It is intended that ABF will recognise all of the background work that contributes to the delivery of a service event. However, PCA is concerned that the breadth and the time required for such background work in palliative care may not be fully acknowledged and resourced. We already know that many GPs are reluctant to provide comprehensive end of life care to residents in RACFs because there is no payment in their fee for service model which compensates for the extensive time and effort in coordination of care whether through phone calls or otherwise. Similarly ABF needs to include compensation for the extent of the background work performed that underpins the delivery of the palliative care service event, especially within the community setting. The time and complexity of communications to coordinate care, multidisciplinary team meetings, and other components such as volunteer management contribute to the unique nature of palliative care. This essential foundation work must be recognised as a component of each service event.

In summary, there is a need to move away from the traditional funding arrangements for palliative care which are based on cancer services, to reflect the fact that Australians are dying now from an increasing range of complex chronic diseases. The guiding principle of funding for palliative and end of life care should be equitable support for all Australians and a flexible system based on individual needs, across all care settings.

Palliative Care for Children and Adolescents

There is a need to recognise that palliative care for children and adolescents is different from palliative care provided to adults. The provision of paediatric palliative care varies widely across Australia, with some states and territories not having dedicated paediatric services. Much of this is to do with the small amount of both quantitative and qualitative data in Australia needed for effective service planning. We do not know the real numbers of children requiring or using palliative care services. We also do not know the age ranges, illnesses or disabilities of these service users.

Health services are increasingly reporting on a group of clients that do not fit neatly into the current system – young adults between 18 and 30. Technology has increased the lifespan of some children who historically would have died in their childhood such as those with cystic fibrosis, non-malignant conditions and those with multiple disabilities. They are discharged from the children's services at 18 and find it difficult to access the range of services they require in the adult system.

Generally, the care and coordination of services for neonates with life threatening conditions happens in maternity hospitals, so access to quality palliative care can be ad hoc. Similarly, for women who decide to proceed with a pregnancy when the child will be born with a life threatening condition, their support is primarily provided by obstetricians. Specialist palliative care, or familiarity with a palliative approach, can improve outcomes for these families. There is a need to ensure that families know what services are available, that care is well coordinated and of high quality, and supported by the best available research and evidence.

2. The effectiveness, efficiency and adequacy of palliative care services

Improved access to palliative care services has the potential to improve both the efficiency and effectiveness of healthcare services for the dying and the healthcare system as a whole:

Efficiency – by avoiding inappropriate and preventable admissions to emergency and acute services, thus, a more cost effective use of health resources. Further, by minimising or avoiding investigations, treatments and procedures that offer no improvement in quality of life.

Effectiveness – by providing better outcomes for patients and their families. A conservative analysis of available data indicates that the cost of palliative care services can be between half and three times less expensive than care in an acute bed or intensive care bed. The estimated costs of this can be broken down as follows:

An Intensive Care Unit (ICU) bed costs around \$4000 per patient, per day, or \$1.5M per bed per year, according to Professor Ken Hillman², who says:

²Professor Ken Hillman is Professor of Intensive Care at the University of New South Wales in Sydney.

“at least half of my ICU patients shouldn’t be there...Dying in ICU is a very cruel, awful way to die.”

Senior Intensive Care Specialist Dr Peter Saul³ says:

“in terms of health costs, our final year of life is our most expensive. Almost all of this expense is in the last few weeks. Dying in an ICU costs more than most of us have ever paid in contributions to the Medicare levy. Nor is it a particularly pleasant experience. Evidence suggests that as many as half the people admitted to an ICU at the end of life would have chosen otherwise had they been given the choice.”

- An acute hospital bed costs more than \$1100 per day on average
- Ambulance callouts cost between \$300 and \$5000
- The cost of palliative care varies depending on where it is provided and the particular needs of the patient, but it has been broadly estimated at between \$200 per day for a patient in a residential aged care facility (RACF), \$600 per day in a hospice that can manage moderate complexity and \$950 per day for an inpatient palliative care facility that is able to manage highly complex patients and families.

Palliative care can play a pivotal role in achieving efficiency in the health system by:

- Making prevention everyone’s business – palliative care can help prevent the types of distressing, often lengthy, costly and unnecessary emergency department attendances that are often followed by acute hospital admissions in the last 6-12 months of a patient’s life.
- Creating better experiences for people using health services. One of the principal aims of palliative care is to enhance quality of life, and create better experiences for patients and their families. Studies have shown that families of patients who have received palliative care and have received bereavement counselling have much better experiences during the terminal phase of their loved one’s illness, have an acceptance of death and lower rates of depression six months after the death.^{4,5}
- Investing more in palliative care services has the double benefit of achieving significant financial savings, and freeing up acute hospital beds.

Palliative care providers throughout Australia report rapidly increasing growth in demand for their services while resources to meet the increased workload have not grown at the same rate. The implication of this is that palliative care services are doing more work with the same amount of resources which raises the question that either efficiency/productivity is

³Dr. Peter Saul is a Senior Intensive Care specialist in the adult and paediatric ICU at John Hunter Hospital, and Director of Intensive Care at Newcastle Private Hospital in NSW.

⁴Dinef O, (1999) Orthodox Perspectives on Death, Dying and Bereavement, Woodville, South Australia, Western Palliative Care Service.

⁵Dying Matters - Raising awareness of dying, death and bereavement - www.dyingmatters.org

improving or quality of care is sacrificed. Evidence from the National Standards Assessment Program(NSAP) and Palliative Care Outcomes Collaboration(PCOC) suggests that quality of care is not, on the whole, being compromised by services. What is being compromised is the population served. With increased demand and reduced or static funding, many palliative care services have needed to restrict their delivery to patients with specific diagnoses such as cancer or motor neurone disease, a short prognosis (e.g. less than 3 months of life expectancy) or patients who are in the community but excluding those in residential aged care facilities. This means that access to high quality end of life care is denied to many patients and families who need it.

The lack of a needs based service delivery model across the country results in inefficient distribution of services with overlap or duplication in some locations, contrasting with a lack of access elsewhere.

A significant gap in efficiency is the absence of strategic planning in palliative care with clear timelines for improvement at state and territory level. The majority of states and territories, including Queensland, do not have current palliative care strategic plans or timelines. This makes planning for service provision, including funding and evaluation of service outcomes, extremely problematic, adding to inefficiencies and ad hoc decision making.

Efficiency of service delivery could also be enhanced by increasing use of advance care plans (supported by appropriate nationally consistent legislation). Such plans should be attached to all eHealth records, along with the inclusion of a person's substitute decision maker, to enable efficient and appropriate service delivery, should the person lose decision making capacity.

In summary, a lack of efficiency in palliative care service provision is underpinned by a lack of planning and strategy in the delivery of services, leading to duplication in some cases. Improvements in palliative care service provision not only results in better care of the dying, but can improve the efficiency of the healthcare system as a whole. The prevention of hospital admissions, emergency admissions, a reduction in the use of acute services, and the minimisation of futile treatments and procedures will result in the co-benefits of financial savings for the health system and freeing up of acute hospital beds for those who need them.

The quality of palliative care provided through primary health care services, including GPs, is variable and largely reliant on the individual knowledge and experience of the GP and the primary health care team. The strength of local networks between health practitioners and services can have a significant impact on the comprehensiveness, timeliness, and adequacy of care received. Too commonly there are poorly established local networks and primary care providers have limited relationships with specialist services.

3. Examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services

Medicare Locals could play a vital leadership role in developing more integrated health services, including developing and implementing the necessary referral criteria and the enhanced workforce education that will be necessary if a truly integrated, multidisciplinary model for palliative care is to be developed. Exactly how this could happen is still problematic. The Department of Health and Ageing discussion paper on governance and functions of Medicare Locals⁶ does not attempt to tackle how GP, specialist and allied health professional service referrals and multidisciplinary team work will be managed, financed, and coordinated to achieve better integration of healthcare services for people with terminal conditions, or indeed needing aged care.

The final report of the National Health and Hospitals Reform Commission (NHHRC) in 2009 recognised the importance of palliative care and made a number of recommendations to improve palliative care services in a range of settings.⁷ They stated that Medicare Locals will work to improve coordination and integration between primary healthcare and other local health services. Medicare Locals will play a key role in linking people to care in remote and rural areas, including:

- Ensuring local primary health care services are better integrated and more responsive to local needs.
- Planning, administering and purchasing after hours services for the local area
- Working with Local Hospital Networks to bring together primary and acute care practitioners and services, to ensure seamless transition by patients between services.

Although the definitive role and function of Medicare Locals is yet to be determined, it has been suggested that they could, if funded, provide specialist palliative care advice and information to residential and community aged care services using specialist nurse practitioners or nurse consultants, in collaboration with GPs (trained in palliative care). Medicare Locals could also have the option to purchase services from state and territory health systems.

The Australian Medicare Local Alliance has identified opportunities to improve the situation for residents within RACFs which include resourcing Medicare Locals to support timely access to GPs and primary healthcare professionals through locally relevant initiatives that address practical and financial barriers to the provision of primary health care services; providing more appropriate funding for the provision of palliative care following a review of current funding arrangements; national roll-out of a systematic approach to advance care planning for residents in aged care facilities; and access to afterhours care, preferably 24/7 services.

⁶Department of Health and Ageing Oct 2010. *Medicare Locals – Discussion Paper on Governance and Functions*, <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/MedicareLocalsDiscussionPaper>

⁷Commonwealth of Australia, *A Healthier Future For all Australians: Final Report of the National Health and Hospital Reform Commission* – June 2009, Australian Government, Canberra, 2009, available online at <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/publications?OpenDocument&ct=National Health and Hospitals Reform Commission>.

In 2003, the Australian Bureau of Statistics estimated that 20% of the Australian population had some degree of disability of whom 6% had a severe disability. Many people with disabilities suffer from diseases that will eventually cause their death, the majority of whom are considered palliative care patients. There are issues for Australians with a disability accessing palliative care services which include:

- The inability to provide 'dying in place'
- Family and carer burnout
- Difficulty locating and accessing specialist palliative care services when required
- Very few services in rural and remote settings
- Palliation is often a medically complex and lengthy process
- Inability to access palliative care funding, due to the blurring of the line between disability and palliation
- Inability to access funding for specialised palliative care equipment.

People with disabilities are often referred to a palliative care service prematurely and have complex needs that do not fall within the current scope of palliative care. Inappropriate referral to a palliative service often arises from the health system that has limited funding streams for patients with disabilities so these patients may end up in alternative, often inappropriate, funded streams.^{8,9}

Many children and young people with palliative care needs also have multiple disabilities. However, the risk or certainty of death in childhood or young adulthood and their changing needs, adds a degree of complexity and urgency to their care and the support that is needed for the family.

Many families will receive a package of care through their state or territory based disability service, which may meet some of their needs at a particular time, but generally disability services are not able to provide:

- Short and longer term in and out of home respite for children with complex medical needs as they do not have the staff with the requisite skills.
- The link between the acute sector, appropriate medical specialists, other health care providers, carers and family.
- Specialist management of symptoms and specialist equipment.
- Psychosocial and bereavement support for all of the family.

If the social and emotional needs of children with life threatening illness and their families are to be fully met, then they must be recognised as a discrete group and be supported to be fully integrated into their local communities. They should have access to appropriate generalist and specialist palliative care services. The reality for many families is that they will have ongoing relationships with a number of providers from a range of sectors including:

⁸Australian Bureau of Statistics, Disability, Ageing and Carers, Australia, cat. no. 4430.0, ABS Ausstats, 2003.

⁹AIHW Australia's Health 2010. Australian Government.

- Specialist palliative care
- Specialist paediatric palliative care
- GPs
- General Paediatric
- Case management
- Disability
- Early childhood
- Education
- HACC
- Religious groups
- Support groups e.g.disease specific or cultural groups; bereavement counselling and support.

Coordination of this extensive range of services is daunting and often falls on the shoulders of the parents. Effective case management is critical to ensuring that care meets the continuously changing needs of the child and family. This is not uniformly available across the country. The challenge of coordination and information provision is further exacerbated when families come from rural and remote areas or a special needs group.

In summary, overall, access to quality care for this population is inconsistent. Ongoing education of disability care professionals, supportive organisational structures and cultures, and intelligent financing solutions, are essential if end of life care for people with disabilities is to improve.