

P A E D I A T R I C P A L L I A T I V E C A R E  
*Australian and New Zealand Reference Group*

SENATE COMMUNITY AFFAIRS COMMITTEE  
THE PROVISION OF PALLIATIVE CARE IN AUSTRALIA

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# Executive Summary

## **Australian Healthcare**

The Australian healthcare system is one of the most effective in the world. It is based on the principles of continuous improvement, innovation, cost effectiveness and patient- and family-centred care. It is also based on the premise of universal access to quality healthcare for all Australians. No one should 'fall through the cracks' in such a system.

## **Children with Life-Limiting Illnesses and their Families**

Paediatric palliative care is an emerging field. While it is relatively underdeveloped relative to its adult equivalent and the evidence base on which to base practice is limited, a number of important initiatives and models of care have emerged internationally in recent years. Yet despite these efforts, children with life-limiting illnesses continue to suffer significantly from inadequate recognition and treatment of symptoms, fear and sadness and aggressive attempts at cure. The trauma experienced by parents, siblings and the wider family from the death of a child is also profound with increased potential for complicated grief reactions, impaired long-term adjustment and even increased mortality. The provision of effective palliative care can be expected to directly benefit the child but also has the potential to be a preventive health intervention for the family, with long term implications for family functioning, mental health, education and employment.

Fortunately in Australia the death of a child is fairly uncommon but it is estimated that 5300 children require palliative care each year. The numbers may be relatively small in comparison to the adult population but the needs are great. These children require specialist care and although efforts are underway to improve the care of this patient group, they continue to 'fall through the cracks'. They often find themselves unsupported by a local community that is fearful of and ill equipped to deal with the death of a child. They may not be able to access specialist care. And they are often unable to access basic supports such as respite, equipment and financial assistance. There are also 'cracks' in the evidence base due to a lack of basic research.

## **Organic Growth**

Fortunately, over the past decade or so, paediatric palliative care services have been championed and developed through the efforts of a small number of committed individuals who have worked on behalf of their patients and families by lobbying for funding and recognition. Existing services in Australia started locally and have achieved limited state level funding to deliver clinical services.

This group of individuals has self-organised by forming the Australian and New Zealand Paediatric Palliative Care Reference Group. This group has taken a leadership role in paediatric palliative care nationally. It operates entirely on the goodwill of its members and receives no funding from any body, state or federal.

## **Where are the 'cracks' in the system?**

Access – not all Australian children with palliative care needs are able to access specialist services.

Practical supports – many families are not able to access the equipment and respite care they need to help them care for their sick child at home.

Research – many of the techniques and practices applied in paediatric palliative care have not been adequately researched.

A national framework – The National Palliative Care Strategy 2010 does not address the specific needs of children. A national framework for paediatric palliative care would be a crucial step towards improving the specialist care of this patient group. There is a huge variation in the supports available and many services are generating their own guidelines and policies when many of these could be shared nationally.

Workforce – there are few individuals with appropriate qualifications in paediatric palliative care.

Advance Care Planning - the recently released National Framework for Advance Care Directives 2011 does not address the specific needs of children.

**What is required?**

1. Formal recognition and support for the Australian and New Zealand Paediatric Palliative Care Reference Group.
2. The development of a national framework for children's palliative care including standards and guidelines.
3. Dedicated funding for research.
4. The development of a paediatric addendum to the National Framework for Advance Care Directives 2011.
5. Additional funding for practical supports such as equipment and respite care.
6. Investment in workforce development and training.

Achieving these outcomes for this relatively small but very significant patient group requires only modest funding and is entirely and immediately achievable.

# Background

In the rush to improve the care of older patients dying from cancer, the needs of children were all but forgotten until the late 1970s. Although paediatric mortality rates have declined dramatically in the last century, children die and they do so from a range of conditions including neurodegenerative disorders, congenital anomalies and malignancy. It is still not known exactly how many children might benefit from palliative care. Many of the life-limiting conditions that affect children are characterised by long illness trajectories, high levels of disability and prognostic uncertainty. These characteristics have major implications for how palliative care is provided to children. Difficulties in accurately predicting if and when a child will die mean that palliative care cannot be positioned as mutually exclusive from ongoing efforts to modify or cure disease. Instead, it must be integrated with these efforts in circumstances where the child faces the probability of death.

Children cannot be viewed as 'little adults'. The diverse range of life-limiting conditions suffered by children, the uncertainty associated with many of these conditions, the influence of development on their experience of illness and the existence of specialist knowledge regarding their management in the paediatric sector means that a different approach is required to the provision of palliative care to children.

## Key Issues

The following key issues are discussed in more detail:

- Children require specialist care
- Access to specialist care
- Efficient use of resources
- Practical supports
- Advance care planning in the paediatric setting
- Research

# Children require Specialist Care

Children and their families have particular needs in relation to palliative care and require the input of specialists in this field. This is because:

- The range of illnesses encountered is very diverse. Only around 30% have a malignant condition.
- The illness course is often unpredictable. Many children are very unwell for many years.
- Growth and development influence aspects of care such as communication, symptom management and decision-making.
- Parents are very involved as care-givers and decision-makers.
- A broad range of sectors are involved in providing care (e.g. health, disability, education).
- Parental grief is particularly severe and prone to complication.
- There is a need to consider siblings, school friends, grandparents and others.
- The death of a child is now relatively uncommon. Community reactions can leave families feeling isolated and health professionals often feel ill-equipped to manage a child with palliative care needs.

Paediatric palliative medicine is a recognised sub-specialty with a dedicated training pathway within the Royal Australasian College of Physicians however there is only one accredited training position in all of Australia.

## **The patient population**

Knowledge concerning the epidemiology of paediatric palliative care is limited. The best available estimate of the number of children and young people requiring palliative care is 16 per 10,000 age 0-19 years. The patient population in paediatric palliative care is heterogeneous and very different from that seen in the adult setting. Approximately 70% of children who require palliative care have non-malignant conditions. Many of these children have neurodegenerative disorders characterised by a slow decline over months to years. Congenital anomalies also account for a significant proportion of children with palliative care needs. These can occur in isolation as fatal abnormalities of the central nervous system or heart, or as part of a constellation of abnormalities which together threaten life. Some of these conditions are very rare or unique. Many are inherited meaning that more than one child is affected in any given family.

## **Prognostic Uncertainty**

For some children, as with many terminally ill adults, a relatively accurate prognosis may be given and information provided about the nature of the condition and the anticipated rate of decline. For many children however, the condition is so rare that little information is available and the prognosis cannot be predicted with certainty. Prognostic uncertainty is a major issue in paediatric palliative care and has implications for service provision. The face of paediatrics is changing and while many previously fatal conditions of childhood can now be either prevented or cured, advances in technology also mean that children who once died early of congenital anomalies, prematurity and other conditions now live for longer periods in states of high dependency. Many of these children are vulnerable to death during childhood with families and the health professionals caring for them negotiating a path of chronic uncertainty.

## **Parents and Siblings**

A central tenet of palliative care is that it involves the provision of support to both patient and family. Where the patient is a child, a range of issues requires consideration. Parents act as direct caregivers and decision-makers and in many ways the needs of the child and the needs of the parents are inextricably linked. There may also be other young children in the family and siblings are known to experience feelings of isolation and sadness that they may not feel able to share with their parents. Without appropriate support there may be a long-term impact on the psychological and emotional wellbeing of siblings.

Parents take on the task of caring for their sick child lovingly and willingly but this commitment often comes at considerable cost to their financial security, employment status, relationships and mental health. A dramatic indicator of this is the higher mortality rate seen among bereaved parents. With adequate support however, some are able to describe positive experiences such as meeting people, learning things and achieving goals they felt they could not have achieved if their child had not become ill. Although the death of a child represents a profound loss, the achievements of surviving family members can effect positive social changes through advocacy and the fruits of individual careers.

### **Developmental Influences**

Childhood is a time of rapid physical, psychological, emotional and spiritual development and from the tiniest newborn to the adolescent, children cannot be viewed as 'little adults'. Rapid physical development and the physiological changes that accompany physical growth influence the ways in which various treatments affect the child as well as the behaviour of medications in the body. Specialist knowledge of paediatric physiology and pharmacology are needed to manage medications in this age group. The developmental status of a child and young person also influences their ability to understand illness and death as well as their capacity to communicate symptoms, concerns and preferences regarding their care.

### **Complexity**

Ensuring a sick child has the best possible quality of life requires the input of many individuals and services. Many children are attending school and those with disabilities attend special schools. Children may also access a range of disability services, respite care, family support groups and equipment distribution services. The way in which services come together to support a child needing palliative care is best illustrated by a hypothetical case example. This case typifies a child living with a life-limiting condition and highlights the number of individuals and agencies that are often involved in providing care, as well as the various care settings in which care may be provided.

*Billy is an eight year-old boy with adrenoleukodystrophy. Although in the final stages of his disease and very unwell, he continues to attend a special school. He is frequently admitted to hospital with respiratory infections. The following individuals and agencies are involved in providing Billy's palliative care:*

- A specialist paediatric palliative care service which helps Billy access services, resources and supports the agencies involved, and provides specialist input regarding decision-making and the management of a range of physical, emotional, psychological and social issues;*
- A community-based general paediatrician who holds an overall picture of Billy's condition, coordinates his medical care, assists the family with decision-making and is involved in managing symptoms;*
- A general practitioner who manages day-to-day issues such as respiratory infections, constipation and pain;*
- Paediatric respiratory, gastroenterology, neurology and orthopaedic specialists who provide advice concerning the management of a range of issues relevant to their individual specialties;*
- Allied health professionals including social workers, physiotherapists and occupational therapists based at the hospital and the school;*
- A paediatric home care program which trains carers to provide respite and also provides a case manager to coordinate care;*
- An equipment distribution service which provides a wheelchair and other aids;*
- A children's hospice which provides out-of-home respite care, support for Billy's parents and siblings and a volunteer who helps with shopping;*
- A local, community-based palliative care service that provides specialist palliative care nursing, counseling and music therapy.*

Navigating such complexity is difficult and time-consuming. Without access to skilled case management, many parents are unable to access and coordinate appropriate supports. This is especially the case for families from culturally and linguistically diverse backgrounds where English is not spoken as their first language.

### **The community is ill equipped to deal with childhood death**

One of the most important factors influencing the practice of paediatric palliative care is the relative rarity with which child death occurs in developed societies. Relatively low infant and child mortality rates influence societal expectations and responses to the death of a child, which is now so unusual as to be perceived as unnatural. This has major implications for how parents experience the development of fatal illness and the death of their child. Families often feel isolated by community reactions driven by a fundamental fear of death. Health professionals are also influenced by the relative infrequency with which death occurs in childhood. A lack of exposure makes it difficult to acquire and maintain skills.

## Access to Specialist Care

There is a fundamental inequity in the provision of specialist paediatric palliative care. Some states are better resourced than others. Tasmania and the territories do not have specialist paediatric palliative care services. Even where a specialist service exists, children are often referred late or not at all. This relates to a number of factors.

1. Many health professionals misunderstand palliative care and see it only as end-of-life care. They may therefore wait until they are certain that the child will die before making a referral for specialist assistance.
2. Health professionals may not be aware of their own limitations and can underestimate the potential 'value add' of a referral to a specialist service.
3. Many families equate palliative care with 'giving up' and losing hope. They do not want to be seen to give up on their child.
4. The uncertainty that surrounds life-limiting illness in children makes it difficult to predict the illness course with accuracy.

More work is required to dispel some of the myths surrounding palliative care. Palliative care needs to be integrated into the overall plan of care where there is more than a 50% chance that the child will die in the next 12 months. Families should not be forced to choose between palliative care and ongoing efforts to cure or control disease.

## Efficient Use of Resources

As in most other countries, paediatric palliative care has not developed in a coordinated way in Australia. Rather, individuals became aware of initiatives overseas and saw opportunities to improve the care provided to children and families locally. Although services have developed independently of one another, there has been a strong and collegial relationship between more experienced clinicians who generously support those newer to the field. This spirit of generosity and willingness to share ideas, experience and expertise has been crucial to the development of paediatric palliative care in Australia. The models in current use are varied and reflect the needs of the local population and the health care resources and systems available. The key challenge in Australia has been to provide an equitable standard of palliative care to a population distributed over an enormous land mass. Resources have been limited and this has led to an analytical and creative approach to service development.

It has not been considered feasible to develop a parallel system of palliative care for children in Australia. Instead, models have developed which leverage, integrate and complement existing resources. In this way, they are

highly efficient. Children are able to access high-quality tertiary paediatric care in the hospital setting but community-based paediatric services are limited. Community-based palliative care services are available but largely adult and cancer-focused. Most specialist paediatric palliative care services in Australia seek to build links between these two sectors so that children can move seamlessly between them. They also seek to add value by providing expertise on palliative care issues in the paediatric setting and on paediatric issues in the palliative care setting. Specialist paediatric palliative care services also work within the disability and education sectors to improve the level of support for very ill children.

With the exception of Tasmania, all Australian states have at least one specialist paediatric palliative care service. Although funding levels, staffing and models vary, all are based at tertiary paediatric centres. At this stage the Northern Territory and the Australian Capital Territory do not have such services but are able to consult with specialists in neighboring states. There are two children's hospices in Australia. Bear Cottage in Sydney is organizationally part of, but physically separate from, the Children's Hospital at Westmead. It is funded through charitable donations. Very Special Kids is both organizationally and physically separate from the Royal Children's Hospital in Melbourne but maintains a strong alliance with the hospital through the Victorian Paediatric Palliative Care Program. It receives some state government funding but is also funded through charitable donations.

In 2002, the Australian Government commissioned a national project to:

1. review existing models of paediatric palliative care;
2. identify areas in need of development; and,
3. identify a model of care that would best meet the needs of children with life-limiting conditions and their families.

This project has not substantially progressed the development of paediatric palliative care in Australia. Only one of a number of major recommendations was acted upon (the creation of a written resource for families) and whilst this was very worthwhile, other equally critical initiatives remain unaddressed (the development of national clinical practice guidelines, development of a national data set, allocation of greater resources, education and training of staff, program evaluation).

The efficiency of existing specialist services could be greatly enhanced if a number of the recommendations of the 2004 Model of Care review were implemented. The first and most important of these would be funding of the activity of the Australian and New Zealand Paediatric Palliative Care Reference Group. This group already has a structure, enthusiastic membership and clear Terms of Reference but its output has been limited by the fact that the group receives no funding, support or official recognition. Its members do not have the resources to meet face-to-face or by teleconference and there is no administrative assistance. Funding support for this group would facilitate:

- The collation of a national dataset to inform priorities for further development.
- The production of resources (e.g. standards, guidelines, service evaluation tools, written materials for health professionals and families) that could be shared nationally.
- The development of a national framework for research through the identification of research priorities and opportunities for multi-site collaboration.
- A national approach to education and training in paediatric palliative care.
- Representation within national bodies such as Palliative Care Australia, the Australian and New Zealand Society of Palliative Medicine, and the Royal Australasian College of Physicians.
- The development of linkages internationally.

Only by coordinating activities across Australia can the field reach a 'critical mass' of expertise. There is a significant need for a nationally funded body to oversee the development of a national framework and to



interface with other government initiatives such as the Palliative Care Outcomes Collaboration (PCOC) and the National Standards Assessment Program (NSAP).

## Practical Supports

Children with palliative care needs could potentially spend less time in hospital if greater support were provided to their families at home. This benefits both the child and the family. It is also cost-effective. Managing a child with a terminal illness at home relieves pressure on the hospital system (from a space and cost perspective). Despite this being the most effective solution in many cases, there are insufficient funds and resources to achieve this outcome. The result is a net increase in total cost to the health system. Parents take on the care of their sick children lovingly and willingly but this commitment comes at a considerable cost to their financial security, employment status, relationships and mental health. Sadly, existing systems often only add to the burden of care through arcane processes that can be complex, time-consuming and frustrating to navigate. Many families struggle to obtain even the most basic supports such as equipment and respite care. Children often have to wait many months and sometimes more than a year, to obtain wheelchairs, hoists and bathing aids. There is usually a substantial financial outlay by the family for these items despite state-government subsidy schemes. Respite is also difficult to access.

Families need:

- Timely access to equipment,
- In- and out-of-home respite options,
- Assistance with case management to help them navigate complex systems and to allow them to spend more time with their sick children.

Three interventions would significantly improve the provision of practical supports:

1. The development of national standards for paediatric palliative care to ensure equity across all states and territories. As already outlined, the Australian and New Zealand Paediatric Palliative Care Reference Group is well-positioned to facilitate this but requires formal recognition and funding support.
2. Additional funding for equipment, respite care and case management for children with palliative care needs. It is hoped the National Disability Insurance Scheme will assist with this.
3. Mechanisms for prioritising children with palliative care needs so they can access basic supports quickly. While it is recognized that all disabled children deserve these supports, children who are dying cannot afford to wait months for services. There are many heart-breaking stories of children who have died while on waiting lists.

## Workforce Development

### *Subspecialist*

Paediatric Palliative Care is now a recognised medical subspecialty with a training pathway within The Royal Australasian College of Physicians. There is however, only one accredited training position in all of Australia. Not all paediatric palliative care services around Australia have access to a medical specialist in this area however. Those that do, usually have access to a single individual. This has implications for leave arrangements, after-hours availability, staff support and sustainability. Similar issues are encountered in the nursing and allied health elements of these services.

Workforce development is urgently needed. All specialist paediatric palliative care services across Australia should be staffed by health professionals with appropriate training and qualifications in this area of practice and there should be plans in place for the ongoing sustainability of these services. Providing a forum for collegial support and the sharing of knowledge among practitioners in this very difficult field of medicine is also crucial. The Australian and New Zealand Paediatric Palliative Care Reference Group could provide such a forum.

#### *Generalist*

Children with palliative care needs require the input of a range of providers. Doctors, nurses and allied health staff from both the paediatric and palliative care sectors are all involved in providing palliative care to children. Building the capacity of these individuals is crucial. This requires basic training at undergraduate and postgraduate levels as well as the creation of resources (e.g. guidelines, policies) to assist at the point of care.

## Advance Care Planning in the Paediatric Setting

Inadequate advance care planning is a barrier to children accessing specialist paediatric palliative care. Specialists in this area are often aware of children who could benefit from their support but who cannot access it because of reluctance by the treating team to make a referral. This is related to a number of factors.

1. Prognostic uncertainty and the ever-increasing technical capacity to maintain and prolong life means that it can be difficult to determine the point at which a referral should be made.
2. Many health professionals within paediatrics understand palliative care only as end-of-life care and wait until they are absolutely certain the child will die before making a referral.
3. No-one wants to feel they are 'giving up' on a child. This means children may be asked to bear a significant burden in the pursuit of cure or continued life.
4. It can be difficult for parents to disentangle their own needs from the needs of the child.

Whether or not a child receives palliative care is often determined by decisions regarding goals of care. The quality of this decision-making process (advance care planning) is therefore a key determinant of access to palliative care. Building the capacity of paediatricians and others to work with parents to make decisions in the child's best interests is critical to enhancing quality of life and minimising suffering. By influencing practice further 'upstream', more timely decisions will be made regarding goals of care and more children will be able to access palliative care.

The recently released National Framework for Advance Care Directives 2011 does not address the specific needs of children. Paediatric practice is sufficiently different to warrant separate attention and an addendum to the national framework would be a useful first step in progressing advance care planning for children.

## Research

The term 'therapeutic orphans' famously applied to children in the late 60's, still applies to children needing palliative care. Many medications are released for use without being adequately researched in the paediatric setting and practitioners in paediatric palliative care are often forced to extrapolate from adult practice when managing symptoms such as pain. There are many other areas of paediatric palliative care that remain unstudied. Children with life-limiting illnesses deserve the same standard of care afforded to patients whose conditions can be cured. It is not acceptable to base their treatment on guesswork and extrapolation.

Given resource constraints, a relatively small patient population and the limited number of researchers in this field, it is crucial that research proceeds in a way that maximizes outcomes. Two interventions would significantly progress research in paediatric palliative care.

1. Formal recognition of, and funding support for, the Australian and New Zealand Paediatric Palliative Care Reference Group. This group could facilitate and coordinate;
  - the identification of nationally agreed priorities for research,
  - multi-site collaboration,
  - mechanisms for translating research findings into practice.

While the group exists and is well-positioned to perform these functions it's activities are limited by the fact that it is entirely unfunded.

2. Dedicated funding for research priorities in paediatric palliative care. There is a need to quarantine specific funding for research into this area. The small population base of patients makes achieving competitive research funding difficult.

## Conclusion

Children with palliative care needs are among the most vulnerable members of our society. The community assumes these individuals are provided with the most comprehensive care imaginable but this is not universally the case. Many continue to endure physical, emotional and psychological suffering and their families are left without the basic supports necessary to provide care. How can this be? The fact that death in childhood is uncommon in a developed society such as ours means that children with life-limiting conditions are not in the consciousness of the average person. They are largely invisible and this translates into inadequate funding and resource allocation.

The purpose of this submission is to highlight the needs of this patient group. Their care is complex and requires specialist input. All children with palliative care needs should be able to access this. To this end, the following recommendations are made:

1. Formal recognition and support for the Australian and New Zealand Paediatric Palliative Care Reference Group
2. The development of a national framework for children's palliative care including standards and guidelines
3. Dedicated funding for research
4. The development of a paediatric addendum to the National Framework for Advance Care Directives 2011
5. Additional funding for practical supports such as equipment and respite care
6. Investment in workforce development and training.

Many of these recommendations were made in the Paediatric Palliative Care Service Model Review of 2004. Sadly, most remain unfunded. For a relatively small investment, the care of children with palliative care needs could be significantly improved.

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