

## **section 6.3: paediatric palliative care**

### **what is the profile of paediatric patients with a life limiting illness?**

In Australia, the death of a child is now a relatively uncommon occurrence, due to decreases in infant mortality, widespread use of vaccination for infectious diseases, antibiotics, improved sanitation and provision of post-natal care. This lack of frequency can make the experience for all those involved in providing care for the terminally ill child, including families, communities and health professionals, even more difficult to come to terms with.<sup>1</sup>

### **general characteristics of this group**

- 40-50% have a malignant diagnosis<sup>2</sup>
- the remaining patients often have a rare disorder including:
  - congenital disorders
  - chromosomal abnormalities
  - neurodegenerative diseases
- wide variety of illness trajectories which are often characterised by a lack of clarity in the transition from a curative to palliative phase and uncertainty regarding prognosis
- the duration of a life limiting illness of a child is usually significantly longer than that of an adult, may span a range of developmental periods and be as long as 15 years<sup>3</sup>
- children may have a high degree of disability and correspondingly high care needs<sup>4</sup>

### **particular issues faced**

- talking with children about dying and death in a developmentally appropriate way
- decision making and the role of anticipatory guidance for episodes of progressive disease
- burden of care for parents and the length of time that the care may be required
- the types of illnesses which present may not be familiar to many health professionals outside of the paediatric arena

### **what may be the impact of caring for a sick child?**

- social isolation
- changes to marital and family dynamics<sup>5</sup>
- financial implications as one or both parents may be required to change their employment status during the child's illness
- accommodation of the child's high care needs including:
  - practical and technical skills required in managing percutaneous gastrostomy and naso-gastric tubes, suctioning, non-invasive home ventilation, parenteral access devices (including infusaports)
  - adjustment to the physical demands of 24 hour care
- the significant impact on all members of the family, particularly healthy siblings<sup>6</sup>
- stress to primary health care providers, including General Practitioners and community nursing staff, due to lack of experience with the particular disease encountered or the intensity of the experience

## **identified needs for families and caregivers**

- practical support in the initial phase of care
- information provision, with information offered that is at a level that the family can understand, presented in a respectful, honest and compassionate manner, and at a pace that matches family requirements<sup>7</sup> – written information in the form of a summary can be helpful, in addition to verbal communication, as it can be taken away and read at a later time
- acknowledgement that fathers and mothers may grieve in different ways and that different communication styles between parents can give rise to misunderstandings or conflict in already tense and stressful situations
- emotional support during the long and protracted course of disease and during any invasive treatment protocols
- self care for parents, particularly mothers, as integral to their own health
- coordination of care, particularly when multiple agencies are involved – this should include school teaching and counselling staff

## **settings of care**

- most families prefer to care for their child at home where the environment is familiar and care for other siblings can be more practically managed
- when inpatient respite or end of life care is required, adult hospices may be considered – families may, however, feel that an acute paediatric hospital is more appropriate to provide this care due to stronger bonds and familiarity
- consider the role of the General Practitioner for whom this may be very unfamiliar territory and who may not have been actively involved in care for some time due to the primary caring role required of the specialist paediatric team
- planning for care in advance helps to clarify with the child and family those elements of care that they do want<sup>8</sup>

## **essential considerations in management**

- symptom management requires not just dose adjustment but also a greater consideration for side-effects – pain management will need to take into account the physiological differences between adults and children which affects all aspects of drug utilisation and excretion<sup>9</sup>
- assessment and reassessment of pain must be performed more frequently in children than in adults to avoid underestimation, particularly for those not yet able to talk
- partnered care with key health care providers, including the specialist paediatric medical team (with whom it is likely that there has been a long relationship), General Practitioner, community nursing and specialist palliative care service
- specialist palliative care services play a critical role in bringing a particular expertise to anticipating and managing symptoms and in coordinating resources to support home based care
- using a variety of approaches to care which include access to:
  - formal and informal community supports
  - respite options (which may be an adult hospice unit)
  - allied health and pastoral care workers
  - play or art therapy
  - complementary therapies, particularly for family and caregivers

Grief and bereavement support for families in these circumstances requires specific expertise and there is a greater risk of complicated grief occurring in bereaved parents.<sup>10</sup> Grief and bereavement support for families in these circumstances requires specific expertise and there is a greater risk of complicated grief occurring in bereaved parents.<sup>11</sup> Providing information and access to locally available support resources for families (eg community health centre or specialist palliative care service) is essential.

## related resources and information for staff

### Paediatric Palliative Care

Children's, Youth and Women's Health Service

72 King William Road

North Adelaide SA 5006

ph 08 8161 7994 Fax (08) 8161 6631, after hours contact 08 8161 7000 pager 5719

**The Royal Children's Hospital, Melbourne** provides a useful website with a general description of Paediatric Palliative Care and links to other relevant websites, see

<http://www.rch.org.au/rch-palliative>

## related texts

*Oxford Textbook of Palliative Care for Children* (2006) Goldman A, Hain R, Liben S.  
Oxford University Press, Oxford, UK.

*Oxford Textbook of Palliative Medicine* (1999) Eds Doyle D, Hanke G, MacDonald. Oxford University Press, Oxford, UK. Chapter 7 Paediatric Palliative Care

*Palliative Care for Infants, Children and Adolescents* (2004). Carter B & Levetown M (Eds)  
John Hopkins University Press, Baltimore.

*Therapeutic Guidelines – Palliative Care, Version 2* (2005)  
Chapter on Paediatric Principles and Practice, pg 127–152.

## resources for families

### Camp Quality

Access to quality recreational, educational and support programs

2/250 Melbourne St

Nth Adelaide

Ph 08 8239 0844

### Canteen (SA Division)

Health information, advocacy, peer support and social activities for children with cancer, their siblings and bereaved siblings for young people 12-24 years of age

Norwich Centre Level

77 King William Rd

Nth Adelaide 5006

Ph 08 8161 7488

**Child and Adolescent Mental Health Services**

Counselling service for children and adolescents to 18 years of age  
Ph 08 8161 7389 for local services

**Childhood Cancer Association Incorporated**

Level 1/55 King William St,  
Nth Adelaide 5006  
Ph 08 8239 1444

***Journeys – Palliative Care for Children and Teenagers***

An information resource for families and caregivers to assist them in managing a life limiting illness of their child or adolescent, see <http://www.pallcare.org.au/> for links.

**Kids Helpline**

Confidential telephone counselling for young people 5-18 years of age  
Ph 1800 55 1800

**Make a Wish Foundation**

Support for children (and their families) under the age of 18 diagnosed with a life limiting illness  
Suite 3, 95 Hay Street  
Subiaco WA 6008  
[www.makeawish.org.au](http://www.makeawish.org.au)  
ph 1800 032 260

**Muscular Dystrophy Association Inc. (MDASA)**

36-38 Henley Beach Rd  
Mile End SA 5031  
Ph 08 8234 5266, 1800 685 266

**SIDS and KIDS**

Information and support networks  
301 Payneham Road  
Royston Park 5070  
<http://www.sidsandkids.org/sa/index.html>

**Star Bear Foundation** Support programs for children who have experienced grief and loss.

[www.starbear@anglicare-sa.org.au](mailto:www.starbear@anglicare-sa.org.au)  
ph 08 8301 4208

**Starlight**

Various programs for seriously ill children in hospitals and through the Starlight Escapes and the Starlight Wish Granting Program  
Lvl 1, 144 North Terrace  
Adelaide SA 5000  
ph 08 8407 2250  
<http://www.starlight.org.au/>

**Ronald McDonald House**

Provides accommodation for rural families whose children require treatment in Adelaide for their life limiting illness  
271 Melbourne St  
Nth Adelaide 5006  
ph 08 8267 6922

## references

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- <sup>1</sup> Hynson J, Gillis J, Collins J, Irving H, Trethewie S (2003) The dying child; how is care different? *MJA* 179 (6 Suppl) S20-S22
- <sup>2</sup> Oxford Handbook of Palliative Care, Oxford University Press. 2005. Chapter 7-Paediatric Palliative Care, pg 443.
- <sup>3</sup> Palliative Care Service Provision in Australia; A planning Guide (2002). Palliative Care Australia, ACT.
- <sup>4</sup> Hynson J, Gillis J, Collins J, Irving H, Trethewie S (2003) The dying child; how is care different? *MJA* 179 (6 Suppl) S20-S22
- <sup>5</sup> *The hardest thing we've ever done: The social impact of caring for the terminally ill in Australia*. Palliative Care Australia. (2004)
- <sup>6</sup> Deely L, Hallard P, Lewis M, Lenton S (1998) Palliative services for children must adopt a family centred approach, *BMJ*; 317:284.
- <sup>7</sup> Steele R (2002) Experiences of families in which a child has a terminal illness: modifying factors. *International Journal of Palliative Nursing*. Vol 8 (9) 418-434.
- <sup>8</sup> Hynson J, Gillis J, Collins J, Irving H, Trethewie S. (2003) "The dying child: how is care different?" *MJA* 179 (6 Suppl) S20-S22.
- <sup>9</sup> Paediatric Palliative Care Service Model Review (2004). Australian Government Department of Health and Ageing, ACT.
- <sup>10</sup> Standards for Providing Quality Palliative Care for all Australians. (2005) Palliative Care Australia, ACT.
- <sup>11</sup> Standards for Providing Quality Palliative Care for all Australians. (2005) Palliative Care Australia, ACT.