



Government of **Western Australia**
Department of **Health**

Palliative care for children and their families



Information for
respite support workers







Produced by the WA Cancer & Palliative Care Network,
Paediatric Palliative Care Reference Group.

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About this booklet

This booklet is designed for people working with children who have life-limiting illnesses and/or their families.

It provides a brief overview of palliative care for children and their unique care needs.

What is palliative care for children?

Palliative care is the term used to describe the care and support given to people with life-limiting illnesses. Paediatric palliative care refers to palliative care for children and their families.

The goal of palliative care is to provide comfort and the best quality of life for children and their families at any stage of their illness, not just when they are nearing the end of their life.



Who needs palliative care?

A small number of children in Western Australia diagnosed with life-limiting illnesses, are not always expected to live to adulthood. The types of life-limiting illnesses that may require palliative care include (but are not limited to) cancer, severe cerebral palsy, neuromuscular conditions, congenital anomalies or extreme prematurity.

Who provides paediatric palliative care?

Palliative care can be provided by all health professionals and care workers. We also have specialist state-wide paediatric palliative care services which are based at Princess Margaret Hospital. These services are staffed by a health care team with specific experience and/or training in the care of children with life-limiting illnesses and their families. The care these services provide can include:

- relief of symptoms (for example, pain, nausea, restlessness and breathing difficulties);
- coordinating care between different medical teams and agencies providing care;
- practical help with equipment, medications and respite care;
- assistance with making decisions about care (for example, feeding and nutrition, medical procedures);
- emotional support for the child and their family
- supporting families and the community to provide care for the child at home;
- education and training about palliative care to families, carers and health professionals.



What is ‘special’ about palliative care for children?

Although there are similarities between the needs of adults and children in palliative care, there are also some differences. These differences impact on the families needs and also affect the way palliative care is provided:

- Only a small number of children require palliative care compared with adults. As a result few services have experience caring for children.
- Some children have illnesses that are very rare. Less than half of the children requiring palliative care have a cancer diagnosis.
- Some illnesses cause the child’s medical and care needs to change suddenly. This requires services and health professionals to be able to respond to the child and family’s needs quickly and efficiently.
- Sometimes children are diagnosed with a condition that may affect their brother or sister as well. In these situations, more than one child in the family may require palliative care.
- Children’s emotional and physical development affects the care they receive (including the medications they can take) and their understanding of their illness.
- The parents, carers and other family members play an active role in caring for the child and are often involved in providing the child’s personal care, medical care and decision making.
- The grief families feel at losing their child is very deep and long lasting. Siblings also require special attention during this time.



What type of services do children and their families need?

Each child and their family have unique needs. Palliative and supportive care services must be flexible and responsive to these needs. Specialist paediatric palliative care services work in partnership with other services to deliver the best quality care for the child and their family.

In Western Australia, five goals of care have been developed to guide the delivery of palliative care for children and their families:

Children and their families will:

1. Receive evidence-based best practice palliative care according to their needs
2. Participate in decision-making and care-planning throughout their care
3. Have access to specialist palliative care at any time during the illness
4. Receive coordinated care
5. Receive care and support in their preferred setting

In most situations, families prefer that care for children is provided in their family home. These children often have high level medical needs which require around the clock care from their family.

Families caring for their child at home will need extra support and guidance. Respite is one way families can 'take a break' from their caring role and attend to their own needs. This should be accessible to all families at short notice.



The paediatric palliative care model of care in Western Australia



The Model acknowledges that there may be multiple organisations or services required to provide the level of care required to meet the needs of children and their families. It is important that all services work together in partnership with the specialist paediatric palliative care services.



What can I do to help?

- **Working with families:** Communicate openly and honestly. It's OK not to have answers to questions - sometimes there are no answers. Respect the family and child's choices for their care. The individual child and family's needs should guide services and care as much as possible.
- **Collaborate:** There can be multiple people and services involved in caring for the child and family. Ask the family who is the 'key person' they want you to contact when planning their care or services. It may be a health professional or someone else working closely with the family.
- **Be flexible:** There is no 'one size fits all' model for paediatric palliative care. When planning care or services, allow for sudden changes in the child's illness and in the families needs, wants or wishes. Regularly review the care or services you provide to make sure it is meeting the child and family's needs.
- **Time is of the essence:** In some instances, children may have been relatively well, only to die within a matter of days or weeks. Make allowances for this and respond quickly where possible to their needs. The aim is to lessen the burden on carers and families as much as possible at this time.
- **Be aware:** People who work with a child who is dying and their family may experience emotional distress. Make sure you have someone to talk to when you need help. Managers and supervisors should ensure their workers have the support needed at this time and have someone to talk to when they need help.
- **Ask for help:** There are experts who can help with caring for a dying child and their family. When you need advice about caring, contact the Paediatric Palliative Care staff for help (contact details are at the end of this pamphlet). You are not expected to have all the answers.



More information?

Paediatric palliative care services in Western Australia can be contacted via the Princess Margaret Hospital switchboard on
Phone: (08) 9340 8222

- If your query is about a child with cancer, contact the Oncology Clinical Nurse Specialist office.

Phone: (08) 9340 8024

- If your query is about a child with an illness other than cancer, contact the Paediatric Palliative Care Program office.

Phone: (08) 9340 7985

Useful websites

WA Cancer and Palliative Care Network
www.healthnetworks.health.wa.gov.au/cancer

Palliative Care Australia
www.palliativecare.org.au

CareSearch
www.caresearch.com.au

International Children's Palliative Care Network
www.icpcn.org.uk





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