



Helen & Douglas House

Palliative Care

TOOLKIT



For professionals working with children who have palliative care needs

The authors and editors have, as far as it is possible, taken care to ensure that the information given in this toolkit is accurate and up-to-date at the time it was created. Helen & Douglas House is not responsible for the content of external web sites. Users are strongly advised to confirm that the information complies with current legislation and standards of practice. Since palliative care and associated commissioning arrangements are part of an evolving process, the current toolkit will be modified as and when required.

Clare Edwards, Director of Clinical Services at Helen & Douglas House commissioned the development of this pack to contribute towards improving practice across the Thames Valley Children's Palliative Care Network. This work was co-ordinated by Helen Carter, Independent Healthcare Advisor. The working party included Karen Brombley, Kathy Patching, Julie Hughes, Laura Chandler, Candida Hazard & Andrea West. The designer was Chris Woodrow. Thanks are extended to everyone from the Thames Valley Children's Palliative Care Network who shared valuable resources to include in this toolkit.

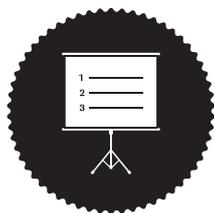
All scenarios used in this toolkit are based on real situations and names have been changed to maintain confidentiality.

October 2011



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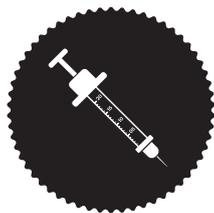
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Introduction

The Department of Health (DH, 2008) recognises that palliative care for children *“starts at diagnosis and is about improving life experiences for children and young people with life-limiting and life-threatening conditions.”*

It acknowledged that the range of illnesses - many of which are rare, and symptoms - many of which are common, makes it hard to define and predict care needs.

Helen & Douglas House successfully bid for Department of Health funding to enhance children’s palliative care services in the Thames Valley area. The bid proposed a number of initiatives including the provision of specialist clinical support, family support and bereavement services and the co-ordination of services across the network. The development of this palliative care toolkit has been one of the initiatives to support staff in their day to day work.

The impact of life limiting diseases in children has wide reaching consequences across the family and wider community. It is well recognised that partnership working is key to developing effective services and this has been reflected in many national documents. Palliative care for children is about providing continuity of care. As a key contributor of the Thames Valley Children’s Palliative Care Network, Helen & Douglas House works collaboratively to develop high quality, accessible and responsive services. A fundamental part of their work is to network effectively and maintain contact with other organisations who offer palliative care to children.

This toolkit has been created for busy clinical staff who work with children with palliative care needs in the region. It aims to provide easily accessible information that will contribute towards the continuity of care that national drivers and the network advocate. In focusing towards improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions this toolkit offers signposts for clinicians who wish to inform their practice and/or quickly pass on knowledge to others.

The areas discussed in this tool kit aim to help staff remain linked with the Thames Valley Children’s Palliative Care Network without having to trawl too much through the plethora of information that is available. It aims to bring together information pertinent to clinical practice at a time when clinicians may be busy. It considers issues of symptom management and offers guidance to ensure a whole package of support can be in place for children and their families. Finally the toolkit aims to help clinicians identify that they are not alone in what can be a very challenging, although rewarding, area of clinical practice.

Where to look

My life would be...“easier if more people understood what is the matter with me so that I didn’t have to keep explaining what is wrong and how to look after me.”

Department of Health (2008) Better Care: Better Lives

Craft and Killen (2007) pointed out the limited understanding of children's palliative care resulting in ad hoc planning and development of services. They also noted that not enough sharing of good practice and inadequate planning meant families were falling through the net.

This toolkit contains a number of useful resources and website addresses for you to use to enhance your own service provision, to keep up to date with changes in children's palliative care and to share information with children and families. As part of the

development of this toolkit we actively encourage the sharing of information and services developments. We hope that the following resources go some way in supporting your work in delivering effective palliative care services for children. Below are some national resources that are of importance and may be of use for clinical staff, children and families.

ACT and Children's Hospice UK have merged to become the one voice for children's palliative care in the UK. Their new name is ACT and Children's Hospice UK.

National resources



Working together to make the most of short lives
www.actchildhospice.org.uk

Further reading

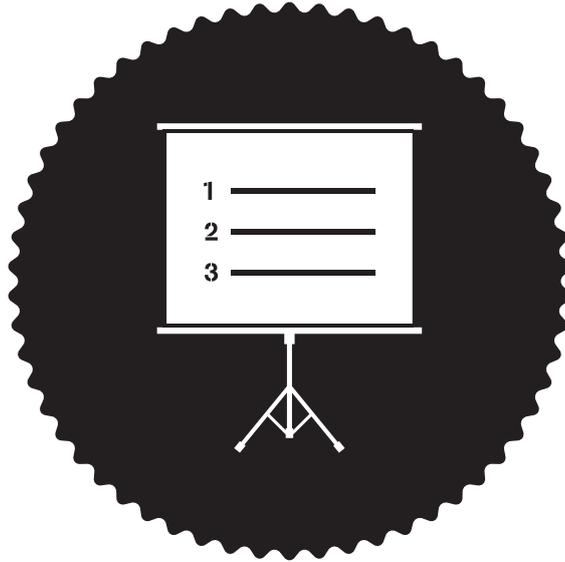
Department for Education and Skills (DfES) (2004) *Every Child Matters: changes for children* London: DfES

Department for Education and Skills (DfES) (2006) *Common Assessment Framework for Children and young people: managers guide; integrated working to improve outcomes for children and young people (Every Child Matters: Changes for Children)* London: DfES

Department of Health (2004) *National Service Framework for children, young people and maternity services: disabled children and those with complex care needs (Every Child Matters: changes for children in health services)* London: Department of Health

Department of Health (2005) *National Service Framework for children, young people and maternity services: commissioning children's and young people's palliative care services (Every Child Matters: changes for children in health services)* London: Department of Health

Department of Health (2005) *National Service Framework for children, young people and maternity services: core standards (Every Child Matters: changes for children in health services)* London: Department of Health



Definitions

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Definition of children's palliative care

"Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement."

Association for Children's Palliative Care/Royal College of Paediatrics and Child Health Guide (2003)

The World Health Organisation (WHO, 1996) defined palliative care as *"The active total care of patients whose disease is unresponsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and other problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families."*

In 1998 the WHO went on to distinguish that palliative care for children:

- | | |
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| <p>1 is the active total care of the child's body, mind and spirit, and also involves giving support to the family.</p> | <p>5 requires a broad multidisciplinary approach that includes the family and makes use of available community resources.</p> |
| <p>2 begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.</p> | <p>6 represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders.</p> |
| <p>3 must evaluate and alleviate a child's physical, psychological, and social distress.</p> | |
| <p>4 can be provided in tertiary care facilities, in community health centres and even in children's homes.</p> | |

Source: www.who.int/cancer/palliative/definition/en (accessed 22/02/11)

“Children’s palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions. It is the need to maintain the quality of life, not just the dying stages, but also in the weeks, months and years before death and is characterised by concern for symptom relief, promotion of general well-being, and psychological and social comfort of the child and family.”

Craft and Killen (2007)

Which children will benefit from palliative care?

Taking the definitions into account there are likely to be more children than initially anticipated who would benefit from palliative care support.

Cochrane, H. Liyanage, S. & Nantambi, R. (2007) identified that:

<p>1 during 2001-05 there were 42,400 deaths in England of children and young people aged 0-39 from causes likely to have required palliative care. This averages at 8,480 per annum.</p>	<p>3 approximately 63% of children and young people requiring palliative care have a need for social care services.</p>
<p>2 over two-thirds of all deaths in the 0-19 age group are from causes likely to have required palliative care.</p>	<p>4 approximately two-thirds of children and young people with palliative care needs also have a disability.</p>

ACT (2011) supports this position by recognising there are over 23,500 children and young people in the UK who have been diagnosed with a health condition for which there is no likelihood of a cure. ACT goes on to identify four broad categories (see table right) of life-threatening and life-limiting conditions where children may benefit from palliative care.

CATEGORY	BENEFIT	EXAMPLES
ONE Life-threatening conditions for which curative treatment may be feasible but can fail.	<ul style="list-style-type: none"> ♥ Where access to palliative care services may be necessary. When treatment fails or during an acute crisis, irrespective of the duration of that threat to life. ♥ On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. 	<ul style="list-style-type: none"> ♥ Cancer, irreversible organ failures of heart, liver, kidney.
TWO Conditions where premature death is inevitable.	<ul style="list-style-type: none"> ♥ Where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. 	<ul style="list-style-type: none"> ♥ Cystic fibrosis, Duchenne muscular dystrophy.
THREE Progressive conditions without curative treatment options.	<ul style="list-style-type: none"> ♥ Treatment is exclusively palliative and may commonly extend over many years. 	<ul style="list-style-type: none"> ♥ Batten disease, mucopolysaccharidoses.
FOUR Irreversible but non-progressive conditions causing severe disability.	<ul style="list-style-type: none"> ♥ Susceptibility to health complications and likelihood of premature death. 	<ul style="list-style-type: none"> ♥ Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

Source: ACT www.act.org.uk/page.asp?section=164§ionTitle=Categories+and+life%2Dlimiting+and+life%2Dthreatening+conditions (accessed 13th May 2011)

Transition: Supporting transition to alternative services



Clare has a complex neurological disorder with intractable epilepsy. She was a regular visitor to the children's hospice and was not expected to reach adulthood.

However at age 16 Clare was still visiting regularly and remained relatively well. Her condition appeared to have stabilised. She was referred to the young adult hospice and following multi-professional assessments it was agreed that she met the criteria for respite care. Once confirmation of a place was agreed Clare's mother was informed. She was very relieved and felt that she too could now look forward again.

Most children and young people do not stay regularly at the hospice so transition is started early to develop links and foster confidence. The transition link worker held a key role during the transition. Clare was allocated a key worker and Clare and her mother were introduced to

him a year before transfer was planned. Clare enjoyed his company and was clearly fascinated by him having been cared for by female carers almost all of her life. Clare visited the hospice for young adults on each of her subsequent stays and her link worker cared for her in the children's hospice on her last stay there. Close links remain for Clare and her mother.

Key aspects of ensuring a successful transition included enabling a long period of time for the process and maintaining close contact between organisations throughout. In addition Clare and her mother were supported to cope with the practical changes, the organisational changes and the different ethos of a young adult hospice compared with a children's hospice. She is successfully integrated and chooses to visit the children's hospice occasionally.

Source: Case study provided by Helen & Douglas House, August 2011

There is a need for effective collaboration between adult and children's palliative care service providers in order to support younger people adjusting to this important life change. Craft and Killen (2007) identified that the current arrangements were

rarely ideal and could result in the sudden transfer of young people to adult services. Alternatively, young people remained in children's services for too long. The ongoing limited availability of adult services also impacts on transition for younger people.

"There are strong indications that, due to advances in medical care, children are living longer and subsequently requiring more palliative care services. Evidence suggests that many of them can maintain a good quality of life if they and their families have access to and are properly managed using appropriate services. However, these children do require increasingly complex levels of support."

Craft and Killen (2007)

Whilst there is a recognition that transition work should begin at aged 14 years old, there continues to be local variation across the Thames Valley. It is likely that some services will require funding prior to engagement. The funding will need to be sought in good time. It is therefore important for clinical staff to keep abreast of what is happening in this area of change in order to support a smoother transition in to adult services.



Pathways

17 Children's palliative care pathways

18 ACT care pathways

Children's palliative care pathways

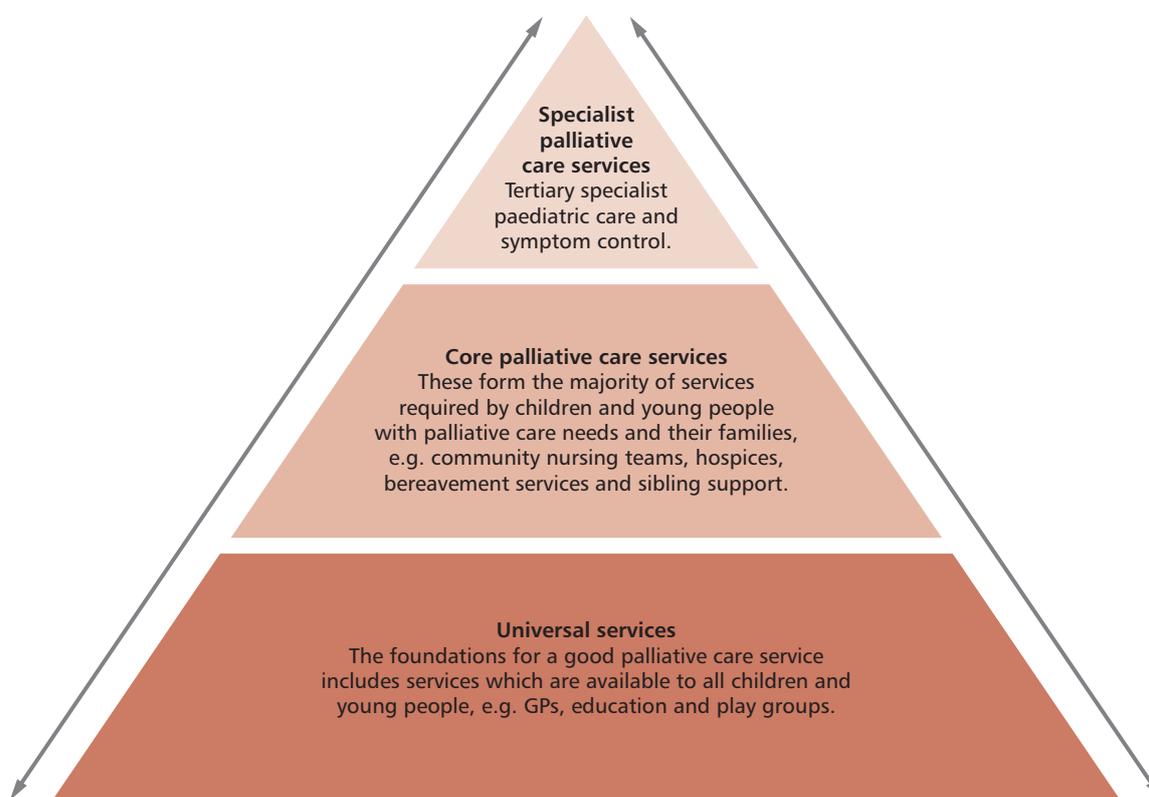
The Department of Health identified that children and young people with palliative care needs and their families should be able to access the services they need according to the different stage of their condition.

Indeed, the review of children's palliative care services in England (Craft and Killen, 2007) noted that a range of accessible services were important elements of good practice. Services can be divided into specialist services - those services that provide specialist paediatric and symptom control; core services – the majority of services such as community nursing teams, hospices, bereavement services and sibling support; then universal services – the day to day services available to all children and young people that can provide the foundation for all care and signposting to other services (Department of Health 2008).

Source: Craft & Killen (2007), Department of Health (2008)

One of Craft and Killen's (2007) recommendations was that "children and young people with palliative care needs and their families should have access to the full range of services on the ACT Care Pathway after an appropriate professional needs assessment". Children's palliative care pathways aim to "help professionals to engage with the child's and family's needs and make sure everything is in place for families to access the support that is right for them."

Source: ACT 2011 www.act.org.uk (accessed 28th June 2011)



Source: Craft & Killen (2007), Department of Health (2008)

My life would be easier if...“I didn’t have to wait months for a wheelchair so that I will have grown out of it by the time I get it – or maybe I won’t even be alive when it arrives.”

Department of Health (2008) Better Care: Better Lives

ACT care pathways

“ACT is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited and life-threatened child, and their family.” (ACT, 2011).

ACT is a UK wide charity that has developed a number of resources that can be downloaded and used by children, parents and clinical staff. The aims of ACT’s care pathways are to maintain continuity of care and promote partnership working across organisational boundaries. The key principles include:

- | | |
|--|---|
| 1 Children and families have their needs assessed as soon as possible after diagnosis. | 6 Information should be systematic and used to ensure consistency. |
| 2 A comprehensive and multi-agency approach should be used to avoid multiple assessments. | 7 Straightforward, non jargon language should be used. |
| 3 Assessment should be in partnership with their family. | 8 Confidentiality and consent should be addressed. |
| 4 The child or young person should be involved in the process. | 9 Assessment information should be made available to families. |
| 5 Individuality and ethnicity should be respected. | 10 There should be clarity in respect of the key lead role. |
| | 11 Those undertaking needs assessments should have appropriate skills and knowledge. |

Source: Adapted from ACT (2011)

The ACT Care Pathway proposes an approach which links children and young people with palliative care needs and their families with community services, hospital based services, social services, education and the voluntary sector in one joined up planning process to ensure continuity of care and promote partnership working.

Source: Page 16 Craft and Killen 2007

Maintaining an effective pathway



Sam was a 4 year old boy who was born with a hypoplastic left heart. He underwent 3 stages of corrective cardiac surgery but unfortunately the third stage was unsuccessful and no further treatment was possible.

Sam had spent most of his life in hospital almost 2 hours away from his home. His parents felt very strongly that they wanted time at home, with family and friends, and that they wanted him to die at home.

The hospital referred him to his local Community Children's Nursing (CCN) team, and to Helen & Douglas House. The Helen & Douglas House Medical Consultant and Nurse Consultant undertook a home visit with the CCN, and

offered ongoing support to the local team as Sam deteriorated. The Nurse Consultant visited weekly with the CCN, and the Helen & Douglas House medical team provided regular telephone symptom management advice.

After 2 weeks Sam's health deteriorated significantly, and the decision was made to start a syringe driver. From this point the telephone support increased to twice daily, and Sam's symptoms were well managed and he died peacefully at home 5 days later. Helen & Douglas House have provided ongoing support to the local team, including debriefing, and to Sam's parents, from the Family Support and Bereavement team.

Source: Case study provided by Helen & Douglas House, July 2011

Below are examples of care pathways developed to support the most effective professional decision making and intervention at the right point of a child's illness.

1 ACT's Integrated Care Pathway for Children and Young People with Life-Threatening or Life-Limiting Conditions and their Families

A tool to help plan and coordinate care for families, children and young people with life-limiting and life-threatening conditions.

→ www.act.org.uk/page.asp?section=114§ionTitle=ACT%27s+care+pathway+for+children

2 A Family Companion to the ACT Care Pathway.

A pathway that acts as a step by step guide to support families in relation to:

- ♥ breaking news.
- ♥ planning for going home.
- ♥ multi-agency assessments of your family's needs.
- ♥ a multi-agency care plan.
- ♥ an end of life plan.

→ www.act.org.uk/page.asp?section=117§ionTitle=A+family+companion+to+the+ACT+care+pathway

3 ACT's Neonatal Care Pathway for Babies with Palliative Care Needs

A pathway for professionals and commissioners to ensure care and resources are available in the right place, at the right time for babies and their families.

→ www.act.org.uk/page.asp?section=116§ionTitle=ACT%27s+neonatal+care+pathway+for+babies+with+palliative+care+needs

4 ACT's Transition Care Pathway

A pathway to help young people and families identify the stages along their journey and enable them to move to adult palliative care services.

→ www.act.org.uk/page.asp?section=115§ionTitle=ACT%27s+transition+care+pathway

5 A Care Pathway to Support Extubation within a Children's Palliative Care Framework

A pathway to support decision making and the process of compassionate extubation across a variety of care settings.

→ www.act.org.uk/page.asp?section=406§ionTitle=A+care+pathway+to+support+extubation+within+a+children%27s+palliative+care+framework

Supporting extubation



Toby was transferred to the hospice from the neonatal unit for withdrawal of life supportive care following lengthy discussions with his parents. Toby had a brain abnormality not felt to be compatible with prolonged life.

Using the ACT guidelines, a plan of care was developed between the parents, neonatal and hospice teams. In addition the community nursing and medical teams were informed of the plan. Toby's parents visited the hospice prior to transfer and the neonatal team attended and remained with Toby and his family whilst monitoring equipment and then ventilation was withdrawn.

A medication protocol had been developed to ensure medication was immediately available should he develop any distressing symptoms. Toby was cradled in his parents' arms and extubated. After an hour without ventilatory support Toby stabilised and his oxygen saturation levels improved. His parents took him outside

into the gardens to spend some private time with him where he continued to breathe well unaided and by the evening appeared stable. Toby slept the night with his parents in one of the hospice family flats with phone calls to the night staff for advice and support as required.

Toby remained settled and stable and his care and symptom management plans were reviewed to support his longer term needs. Toby continued to make progress and had several weekends at home and was then discharged home after one month in the hospice.

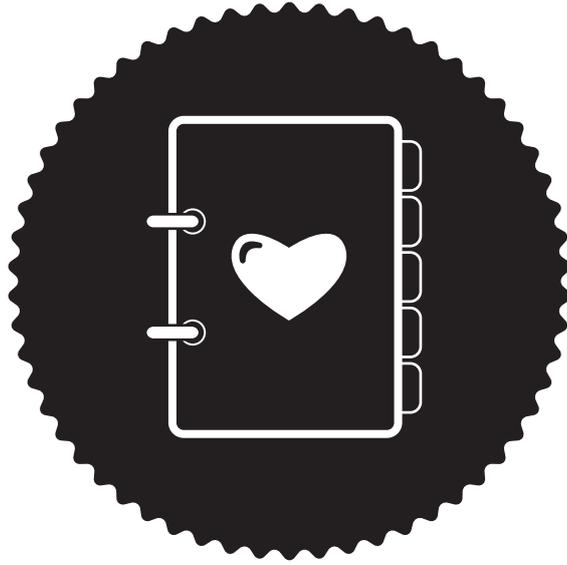
Links were made with his community nursing and medical teams, health visitor and allied health professionals. Toby does have ongoing complex needs but his parents were nurtured through this challenging period and appropriate plans for his future care needs developed. Toby and his family and the community teams will continue to access the hospice as needed.

Source: Case study provided by Helen & Douglas House, August 2011

What do families want?

→ More community based services.	→ More responsive services able to deal swiftly with changing circumstances (e.g. the need for a new wheelchair, deterioration in a child's condition).
→ More respite care, particularly in the community.	→ More bereavement support and support for siblings.
→ Key services available 24 hours a day, 7 days a week, especially for crises and end of life care.	→ Confidence that the services they valued most would be sustained.
→ Assessments coordinated between health and social care, with services to follow.	

Source: Page 25 Craft and Killen 2007



Information & Advice

23 Information, advice & help lines

29 Books for families and siblings

30 Marie Curie leaflets

Information, advice & help lines

Please note that this list is not exhaustive. There are further sources of help and advice on the Helen & Douglas House website and you are recommended to view the latest *Contact a Family* directory.

RESOURCE	CONTACT INFORMATION	INFORMATION
<p>Association for Children with Life Threatening Conditions <i>Now ACT & Children's Hospice UK</i></p>	<p>ACT & Children's Hospice UK 4th Floor, Bridge House 48-52 Baldwin Street Bristol BS1 1QB</p> <p>Helpline: 0845 108 2201 E: info@actchildhospice.org.uk W: www.actchildhospice.org.uk</p>	<ul style="list-style-type: none"> ♥ National helpline for families and professionals. ♥ Website provides information for families and professionals. ♥ Hosts PaedPalCare – a free mailing group for on line queries. ♥ Hosts PaedPalLit – twice yearly publication of relevant journal abstracts.
<p>Batten Disease Family Association</p>	<p>Batten Disease Family Association PO Box 504 Fleet GU51 9GE</p> <p>T: 01252 416110 E: info@bdfa-uk.org.uk</p> <p>Support Tel: 01233 639526 E: support@bdfa-uk.org.uk W: bdfa-uk.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides a national support network and undertakes research projects into patient support and clinical assessment to inform their support provision.
<p>BLISS</p>	<p>BLISS 68 South Lambert Road London SW8 1RL</p> <p>Helpline: 0500 618 140 W: www.bliss.org.uk</p>	<ul style="list-style-type: none"> ♥ Advice, support and information for parents of premature babies, special care or sick babies and for bereaved parents. ♥ Provides a range of publications and fact sheets.
<p>Cerebra</p>	<p>Cerebra 2nd Floor Offices, The Lyric Buildings King Street Carmarthen SA31 1BD</p> <p>T: 01267 244200 E: enquiries@cerebra.org.uk</p> <p>Parent Support FREEPOST SWC3360 Carmarthen SA31 1ZY</p> <p>Helpline: 0800 328 1159 E: info@cerebra.org.uk W: www.cerebra.org.uk</p>	<p>Through research, education and directly supporting children with brain related conditions and families, help and information includes:</p> <ul style="list-style-type: none"> ♥ help in your area. ♥ grants. ♥ sleep service. ♥ stress helpline. ♥ conditions. ♥ childcare & respite. ♥ disability rights & legal issues. ♥ treatments & therapies.
<p>Childhood Bereavement Network</p>	<p>Childhood Bereavement Network 8 Wakeley Street London EC1V 7QE</p> <p>T: 020 7843 6309 E: cbn@ncb.org.uk W: www.childhoodbereavementnetwork.org.uk</p>	<ul style="list-style-type: none"> ♥ National multi-professional federation of organisations and individuals working with bereaved and young people. ♥ Provides a range of resources for young people who are bereaved. ♥ Provides links to local and national networks.
<p>Child Bereavement Charity</p>	<p>Child Bereavement Charity The Saunderton Estate Wycombe Road Saunderton Buckinghamshire HP14 4BF</p> <p>Support & Information Service T: 01494 568900 E: support@childbereavement.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides supporting to families when a child dies and when a child is bereaved. ♥ Advocates for bereaved children, young people and those supporting them. ♥ Supports professionals to find and share knowledge and resources. ♥ Signposts families, professionals and the public to sources of bereavement support. ♥ Phone lines are open Monday to Friday, 9am-5pm.

RESOURCE	CONTACT INFORMATION	INFORMATION
Child Death Helpline	<p>T: 0800 282 986</p> <p>Free number for mobile phones: 0808 800 6019</p> <p>E: contact@childdeath.org.uk</p> <p>W: www.childdeathhelpline.org.uk</p>	<ul style="list-style-type: none"> ♥ Available for anyone affected by the death of a child. ♥ The helpline is open every day throughout the year. Every evening 7pm-10pm Monday to Friday 10am-1pm Tuesday and Wednesday 1pm-4pm Calls are answered by a bereaved parent. ♥ An interpreting service is available.
Childline	<p>Freephone: 0800 11 11</p>	<ul style="list-style-type: none"> ♥ Helpline for children and young people up to the age of 18 years old in danger, distress or any problems.
Children's Hospices (UK) <i>Now ACT & Children's Hospice UK</i>	<p>ACT & Children's Hospice UK 4th Floor, Bridge House 48-52 Baldwin Street Bristol BS1 1QB</p> <p>Helpline: 0845 108 2201</p> <p>E: info@actchildhospice.org.uk</p> <p>W: www.actchildhospice.org.uk</p>	<ul style="list-style-type: none"> ♥ Holds information about how to refer children to hospices. ♥ Provides information for professionals about children's hospice care.
CLIC Sargent	<p>CLIC Sargent Head Office Griffin House 161 Hammersmith Road London W6 8SG</p> <p>T: 0300 330 0803</p> <p>W: www.clicsargent.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides support, advice and information for children with cancer and their families. ♥ During treatment – providing specialist nurses, play specialists, Homes from Home. ♥ In hospital and at home – offering specialist social care and support in the community – services for young people, holidays, grants. ♥ After treatment – helping survivors, supporting those bereaved.
Compassionate Friends	<p>T: 0845 123 2304</p> <p>Available daily from 10am-4pm & 7pm-10pm</p> <p>W: www.tcf.org.uk</p>	<ul style="list-style-type: none"> ♥ A charity dedicated to the support and care of bereaved parents, siblings, and grandparents who have suffered the death of a child. ♥ The line is always answered by a bereaved parent.
Contact a Family	<p>Contact a Family 209-211 City Road London EC1V 1JN</p> <p>T: 020 7608 8700 F: 020 7608 8701</p> <p>Freephone for parents and families Helpline: 0808 808 3555 or Textphone: 0808 808 3556</p> <p>E: info@cafamily.org.uk or helpline@cafamily.org.uk</p> <p><i>The Contact a Family Directory</i> outlines specific conditions, rare disorders and UK family support groups. Similarly there are Contact a Family Resource Packs. Both are useful resources for families and professionals.</p> <p>W: www.cafamily.org.uk</p>	<p>Provides information, advice and support to families and professionals caring for children with disabilities. Including help with:</p> <ul style="list-style-type: none"> ♥ benefits or tax credit issues. ♥ assessments and statements of special educational needs. ♥ details of local parent support groups. ♥ details of Contact a Family services in your area, including one-to-one support, family events and parent workshops. ♥ information about your child's condition. ♥ how to access help with getting a break from caring. ♥ details of charities which give grants to families with disabled children. ♥ advice and information on any other aspect of caring for a disabled child. Available Monday to Friday 9.30am-5pm. ♥ Connected is Contact a Family's quarterly magazine.

RESOURCE	CONTACT INFORMATION	INFORMATION
<p>Cruse bereavement care helpline</p>	<p>Cruse Bereavement Care PO Box 800 Richmond Surrey TW9 1RG</p> <p>T: 0116 288 4119 Young Person's Helpline: 0808 808 1677 Young Person's Website: www.rd4u.org.uk Day by Day helpline: 0844 477 9400 W: www.cruse.org.uk</p>	<ul style="list-style-type: none"> ♥ Cruse Bereavement Care is the major UK charity offering support to bereaved people, whatever their situation. ♥ Provides information or practice and financial advice or information about local support groups. ♥ Provides a listening service. Many local branches offer individual or group support for bereaved children. ♥ Day by Day helpline is available Monday to Friday 9.30am-5pm.
<p>Daisy's Dream</p>	<p>Daisy's Dream PO Box 4738 Twyford Reading Berkshire RG10 9GT</p> <p>T: 0118 934 2604 F: 0118 934 9696 E: info@daisysdream.org.uk W: www.daisysdream.org.uk</p>	<p>Daisy's Dream supports children and their families affected by both life threatening illness and bereavement, throughout Berkshire and the surrounding areas.</p> <p>Provides a range of services which include:</p> <ul style="list-style-type: none"> ♥ telephone advice and support. ♥ direct work with children and young people either at home or school. ♥ opportunities for children and families to meet together and share their experiences at group events that take place throughout the year.
<p>Disability Living Allowance for Children</p>	<p>T: 0800 882200 to request claim pack</p>	<ul style="list-style-type: none"> ♥ A guide to claim disability living allowance for children: www.cafamily.org.uk/pdfs/DLA_factsheet.pdf ♥ Department of Work and Pensions 2010 document can be downloaded from www.dwp.gov.uk/docs/dlaca5dcs.pdf
<p>Dingley Family and Specialist Early Years Centres</p>	<p>Reading Kennet Walk Community Building Kenavon Drive Reading RG1 3GD</p> <p>T: 0118 327 7424 E: admin.reading@dingley.org.uk</p> <p>West Berkshire The Picnic Enclosure Newbury Racecourse Newbury RG14 7NZ</p> <p>T: 01635 552458 E: admin.westberks@dingley.org.uk</p> <p>Wokingham Wokingham Hospital Barkham Road Wokingham RG41 2RE</p> <p>T: 0118 989 4021 E: admin.wokingham@dingley.org.uk</p>	<ul style="list-style-type: none"> ♥ A charity that provides places for children, from birth to five years, with special needs and disabilities to develop skills through therapeutic play. ♥ Reading offers five sessions in the mornings. Monday to Friday 9.15am-12.15pm and three sessions in the afternoon, Monday, Tuesday and Thursday 12.45pm-2.45pm. ♥ The West Berkshire group, based at the Newbury Racecourse, supports children and their families across the West Berkshire area, from Pangbourne and Calcot in the east, to Hungerford and Lambourne in the West. ♥ The Wokingham group is based in dedicated facilities at the Wokingham Hospital.
<p>Duchenne Family Support Group</p>	<p>DFSG 78 York Street, London W1H 1DP</p> <p>Helpline: 0800 121 4518 T: 0870 241 1857 E: info@dfsg.org.uk W: www.dfsg.org.uk</p>	<ul style="list-style-type: none"> ♥ The DFSG helps brings families together who have children diagnosed with Duchenne Muscular Dystrophy (DMD) and for mutual support, sharing of information and experience, and social activities such as subsidised Annual Group Holiday, outings and events, workshops and an annual conference. ♥ Helpline available Monday to Friday 9am-12pm and an answering service is available outside those hours.

RESOURCE	CONTACT INFORMATION	INFORMATION
Foundation for the Study of Infant Deaths (FSID)	<p>FSID 11 Belgrave Road London SW1V 1RB</p> <p>T: 020 7802 3200 (general enquiries) E: office@fsid.org.uk</p> <p>Freephone: 080 8802 6868 E: helpline@fsid.org.uk W: fsid.org.uk</p>	<ul style="list-style-type: none"> ♥ Helpline for parents, carers and health professionals and bereaved families. ♥ Publications and resources on reducing the risk of cot death and safe baby care. ♥ Training, events and family days out in the UK. ♥ Care of Next Infant (CONI) Scheme, with the NHS, to support bereaved families when they have subsequent babies.
Grief Encounter	<p>Grief Encounter Project PO Box 49701 London N20 8XJ</p> <p>T: 020 8446 7452 E: contact@griefencounter.org.uk W: www.griefencounter.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides a helpline offering information, signposting and advice. ♥ One to one counselling, children's workshops, or whole family support. ♥ Training and outreach work for professionals in their own contexts.
Heartline Association	<p>HeartLine Association 32 Little Heath London SE7 8HU</p> <p>T: 033 00 22 44 66 E: admin@heartline.org.uk W: www.heartline.org.uk</p>	<ul style="list-style-type: none"> ♥ For parents of children with heart disease, including a bereavement group.
Help the Hospices	<p>Help the Hospices Hospice House 34-44 Britannia Street London WC1X 9JG</p> <p>T: 020 7520 8200 F: 020 7278 1021 E: info@helpthehospices.org.uk W: www.helpthehospices.org.uk</p>	<ul style="list-style-type: none"> ♥ The leading charity supporting hospice care throughout the UK. Provides support and information for professionals and patients. ♥ Provides an 'Intelligence Hub' that collects, publishes and shares information on hospices and hospice care in the UK. Available at www.hospiceinformation.info
International Children's Palliative Care Network (ICPCN)	<p>W: www.icpcn.org.uk</p>	<ul style="list-style-type: none"> ♥ The ICPCN is a worldwide network of individuals and agencies working with children and young people with life-limiting conditions.
Lifelites	<p>Lifelites Ground Floor, 26 Great Queen Street London WC2B 5BL</p> <p>T: 020 7440 4200 F: 020 7831 4094 E: info@lifelites.org W: www.lifelites.org</p>	<ul style="list-style-type: none"> ♥ Provides technology and high tech entertainments, to give children in hospices the chance to spend quality time with their families, keep in contact with their school and friends, and simply to enjoy themselves.
Macmillan Cancer Line	<p>Macmillan Cancer Support 89 Albert Embankment London SE1 7UQ</p> <p>T: 020 7840 7840 F: 020 7840 7841 W: www.macmillan.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides practical, medical and financial support and advocates for better cancer care. ♥ Open Monday to Friday 9am-9pm.
Mencap	<p>Mencap 123 Golden Lane London EC1Y 0RT</p> <p>T: 020 7454 0454 E: information@mencap.org.uk W: www.mencap.org.uk</p> <p>Local Groups include: W: www.readingmencap.org.uk E: reading-mencap@btconnect.com</p>	<p>A UK charity for people with a learning disability and their families. Local groups share the same aims as Mencap but are local independent charities. They are of different sizes and offer different services. There are three types:</p> <ul style="list-style-type: none"> ♥ Local Mencap groups – these groups might do things like fundraising, campaigning and advocacy. They might also run services or leisure activities. ♥ Gateway Clubs – mainly provide social and leisure activities. ♥ Some groups don't use the name Mencap or Gateway but are affiliated to Mencap and might focus on fundraising, campaigning, run services or leisure activities.

RESOURCE	CONTACT INFORMATION	INFORMATION
Muscular Dystrophy Campaign	Muscular Dystrophy Campaign 61 Southwark Street London SE1 0HL T: 020 7803 4800 E: info@muscular-dystrophy.org W: www.muscular-dystrophy.org	<ul style="list-style-type: none"> ♥ Funds research. ♥ Offers information and advice about care and support. ♥ Provides grants towards equipment. ♥ Campaigns to raise awareness about MD.
National Association of Funeral Directors	National Association of Funeral Directors 618 Warwick Road Solihull West Midlands B91 1AA W: nafd.org.uk	<ul style="list-style-type: none"> ♥ Provides details of member funeral directors in your area.
Paediatric Pain Profile	Dr Anne Hunt Senior Research Fellow in Children's Palliative Care Room 414, Brook Building, Department of Nursing University of Central Lancashire Preston PR1 2HE T: 01772 895148 F: 01772 894968 E: ahunt@uclan.ac.uk W: www.ppprofile.org.uk	<ul style="list-style-type: none"> ♥ Developed the assessment tool to be used for children with severe physical and learning impairments who are in pain.
Rainbow's Trust	<p>South Central Team (Covers Hampshire, Dorset and South Wiltshire) 2 Northam Business Centre Princes Street Southampton SO14 5RP T: 02380 232129 E: margaret.storey@rainbowtrust.org.uk</p> <p>South West Team (Covers Swindon, North Wiltshire, parts of Bath, Somerset and South Oxfordshire) Spittleborough Farm House Swindon Road Wooton Bassett Wiltshire SN4 8ET T: 01793 841204 F: 01793 250134 W: www.rainbowtrust.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides emotional and practical support to families who have a child with a life threatening or terminal illness. Contactable 24 hours a day for families in crisis form diagnosis through treatment and after bereavement.
React <i>(Rapid Effective Assistance for Children with Potentially Terminal illness)</i>	React St Luke's House 270 Sandycombe Road Kew Surrey TW9 3NP T: 020 8940 2575 F: 020 8940 2050 W: www.reactcharity.org	<ul style="list-style-type: none"> ♥ Works to improve the quality of life for financially disadvantaged children with life-limiting illnesses living in the UK. ♥ Responds quickly to requests for help e.g. for equipment or specialist care following recommendations from medical professionals. ♥ Offers family holidays.
Sands <i>(Stillbirth and Neonatal death charity)</i>	Sands 28 Portland Place London W1B 1LY Office: 020 7436 7940 National Helpline: 020 7436 5881 E: helpline@uk-sands.org W: www.uk-sands.org	<ul style="list-style-type: none"> ♥ Offers support for bereaved families and information for professionals caring for bereaved families. ♥ Undertakes research to reduce stillbirths and neonatal deaths. ♥ The helpline is for anyone who has been affected by the death of a baby and wants to talk to someone about their experience.

RESOURCE	CONTACT INFORMATION	INFORMATION
Sand Rose Project	Sand Rose Project PO Box 70 Hayle TR27 5WY T: 0845 6076357 E: info@sandrose.org.uk W: www.sandrose.org.uk	<ul style="list-style-type: none"> ♥ Offers free breaks in Cornwall for bereaved families with children. ♥ Office hours Monday and Wednesday 9am-3pm.
Seasons for Growth	Seasons for Growth 47 Cumberland Street London SW1V 4LY T: 020 7828 0778 W: seasonsforgrowth.co.uk	<ul style="list-style-type: none"> ♥ Seasons for Growth is a group peer-support programme, rather than individual counselling. It is available for young people aged 6-18 years and adults.
Sebastian's Action Trust	E: info@sebastianactiontrust.org for information about 'Reflections' the group for bereaved families. T: 01344 622500 W: www.sebastiansactiontrust.org	<ul style="list-style-type: none"> ♥ Bluebells is a purpose built facility that provides free holidays for seriously ill children and their families. ♥ Sebastian's Action Trust provides practical support for families with sick children including sibling activity days, well-being afternoons for tired mums and transport for hospital visits. ♥ Welcomes families from any area.
See Saw	See Saw Bush House 2 Merewood Avenue Oxford OX3 8EF T: 01865 744768 E: info@seesaw.org.uk W: www.seesaw.org.uk	<ul style="list-style-type: none"> ♥ Helps children and their families before and after bereavement. ♥ Offers advice to parents, carers, teachers and other professionals.
SWAN <i>(Syndromes Without a Name)</i>	T: 0207 704 3141 F: 0207 704 3141 E: SWAN@geneticalliance.org.uk W: www.undiagnosed.org.uk	<ul style="list-style-type: none"> ♥ Campaigns on behalf of families who have a child with an undiagnosed condition. ♥ Provides support and information and a listening ear. ♥ Links families for mutual support and exchange of information.
Thomas's Fund	Thomas's Fund Northampton School For Girls Spinney Hill Road Northampton NN3 6DG E: Thomas@nsg.northants.sch.uk W: www.thomassfund.org.uk	<ul style="list-style-type: none"> ♥ Provides music therapy in Northamptonshire for children and young people with life-limiting illnesses or a disability which, for medical reason, means they are too ill to attend school for extended periods.
Winston Wish	Winston Wish Unit 5, Crawley Business Centre Stephenson Way, Three Bridges Crawley RH10 1TN T: 01293 934583 E: info@winstonswish.org.uk W: www.winstonswish.org.uk	<ul style="list-style-type: none"> ♥ A charity for bereaved families that offers practical support and guidance to families, professionals and anyone concerned about a grieving child.
Well Child	Well Child 16 Royal Crescent Cheltenham Gloucestershire GL50 3DA T: 0845 458 8171 F: 01242 530008 W: www.wellchild.org.uk	<ul style="list-style-type: none"> ♥ Helps sick children and their families throughout the UK to manage the consequences of serious illness and complex health conditions through a programme of care, support and research.

Sources: Accessed 29th March 2011, 4th June 2011, 30th June 2011

Books for families, siblings and health professionals

BOOK	AUTHOR
<i>Fred</i>	Posy Simmonds
<i>What on Earth Do You Do When Someone Dies?</i>	Trevor Romain
<i>Beginnings and Endings and Lifetimes in Between</i>	Bryan Mellonie & Robert Ingpen
<i>I'll Always Love Him</i>	H. Wilhelm
<i>A Dragon's Tale</i>	Jacqui Grove
<i>Sad Isn't Bad</i>	Michaelene Mundy
<i>Gentle Willow</i>	Joyce C. Mills
<i>I Miss You</i>	Pat Thomas
<i>Where's Jess?</i>	M. Johnson
BOOKS FOR CHILDREN AT PRIMARY SCHOOL AGE	
<i>Goodbye Mousie</i>	Robie Harris
<i>When Dinosaurs Die</i>	Laurie Krasney Brown and Mark Brown
<i>Gentle Willow</i>	Joyce Mills
<i>Badger's Parting Gift</i>	Susan Varley
<i>Milly's Bug-nut</i>	Jill Janney
<i>Vicky Angel</i>	Jacqueline Wilson
<i>Water Bugs and Dragonflies</i>	D. Stickney
<i>Charlotte's Webb</i>	E.B. White
<i>Badger's Parting Gift</i>	Susan Varley
<i>What's Heaven?</i>	Maria Shriver
<i>The Frog Who Longed for the Moon to Smile</i>	Margaret Sunderland
<i>The Day the Sea Went Out and Never Came Back</i>	Margaret Sunderland
<i>Why Do People Die?</i>	Cynthia MacGregor
<i>Freddie the Leaf</i>	Leo Buscaglia
<i>When People Die</i>	S. Leвете
<i>What Do We Think About Death?</i>	K. Bryant-Mole
BOOKS ON COPING STRATEGIES	
<i>A Niffleloo Called Nevermind</i>	M. Sunderland
<i>The Huge Bag of Worries</i>	V. Ironside
WORKBOOKS	
<i>Muddles, Puddles and Sunshine</i>	D. Crossley (Winston's Wish Publications)
<i>When Someone Special Dies</i>	M. Heegaard
<i>Finding a Way Through When Someone Close has Died</i>	Pat Wood & Lesley Whittaker
FOR TEENAGERS	
<i>A Summer to Die</i>	Leo Lowry
<i>Healing Your Grieving Heart for Teens: 100 Practical Ideas</i>	A.D. Worfelt
<i>How Teenagers Cope with Grief: Something I've Never Felt Before</i>	Doris Zadanski
<i>Straight Talk About Death for Teenagers</i>	Earl Grollman
<i>Tiger Eyes</i>	Judy Blume
<i>On Eagles' Wings You Can Fly</i>	Sue Mayfield
<i>The Grieving Teen: A Guide for Teenagers and Their Friends</i>	Helen Fitzgerald
Workbook	
<i>Out of the Blue: Making Memories Last When Someone has Died</i>	Winston's Wish Publications

continues overleaf

BOOK	AUTHOR
PARENTS/ADULTS	
<i>Coping with Bereavement</i>	Hamish McIlwraith
<i>How to Survive Bereavement</i>	Andrea Kon
<i>How to Survive the Loss of a Child: Filling the Emptiness and Rebuilding Your Life</i>	Catherine Sanders
<i>Standing on His Own Two Feet</i>	Sue Grant
<i>If the Spirit Moves You</i>	Justine Picardie
<i>Relative Grief</i>	Clare Jenkins & Judy Merry
<i>In Our Own Words</i>	Clare Jenkins & Judy Merry
HEALTH PROFESSIONALS	
<i>Then, Now and Always. Supporting Children as They Journey Through Grief: A Guide for Practitioners</i>	Julia Stokes

Source: Children's Community Health Services, Leicester City Community Health Service (2009) *After Your Child has Died Booklet*. & Iain Rennie Grove House Hospice Care (2011)

Marie Curie leaflets – free downloads

Talking to Children About Terminal Illness

→ www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/Updated-pdf/talking-children-when-someone-close-ill.pdf

Helping Children When Someone Close Dies

→ www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/Updated-pdf/helping-children-when-someone-dies.pdf

Questions Children May Want to Ask When Someone Close to Them Has Died

→ www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/Updated-pdf/question-children-ask-about-death.pdf

Teenage Grief – Things You Might Want to Know

→ www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/Updated-pdf/teenage-grief-guide.pdf

(accessed 1st August 2011)



Providers

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Providers of children's palliative care

“When a child is diagnosed with a life-limiting or life-threatening condition, a multi-agency care team is assigned to the case. This team will include a wide range of professional from different disciplines and specialities and you. You should make the most of having this team around you, especially those who work regularly in children's palliative care, by drawing on their expertise and experience in this area for support.”

ACT (2011)

It will also be helpful to consider if you need to make use of an interpreter or translation services. These will vary depending on the organisation you work for however language line is a

common provider of telephone interpretation for which you will need an identified code for your service. This should be available from your line manager.

Working together



Emma was born with a life-limiting condition which meant she was unable to walk, talk or eat unaided and she had complex health needs. She was the second of four children and her siblings were unaffected by the condition.

Emma received care at home from the Iain Rennie Grove House Hospice Care (IRGH) Children's team and accessed support from Helen & Douglas House (HDH). Services included planned respite and emergency care at times of illness and deterioration in her condition. The family also received social and psychological support.

Emma's condition gradually deteriorated over a few years where she developed frequent chest infections and her recovery became slower. Whilst there were periods when she was relatively well, she often needed oxygen during times of illness.

Emma's family were aware of her prognosis but her parents were often at different stages of acceptance and

had difficulty in recognising the general deterioration in her condition and the potential impact that each bout of ill health brought. Her parents separated when she was six years old which added to the stresses on the family.

One Thursday Emma was sent home from school unwell. An IRGH nurse visited and arranged for the GP to do a home visit and oral antibiotics were prescribed. Over the course of the weekend Emma received visits each day. Her condition deteriorated to the point where she was not responding to antibiotics or chest physiotherapy. Following medical advice, Emma's family decided that they wanted Emma to go into hospital for intravenous antibiotics and appropriate treatment but not to receive intensive care. It became apparent that Emma was not going to survive and immediate transfer to HDH was arranged. Emma and her family undertook the journey within a couple of hours and Emma died there peacefully, a few hours later with her family around her.

Source: Case Study provided by Iain Rennie Grove House Hospice Care, June 2011

My life would be easier if...“mummy and daddy could get help at home to look after me as soon as they need it so they didn't have to manage on their own.”

Department of Health (2008) Better Care: Better Lives

Providers of children's palliative care and specialist respite care services in Thames Valley

Helen & Douglas House, based in Oxford, provides respite care and emergency admissions for symptom control or end of life care for children and young people aged 0-35 years with life limiting and shortening conditions. They also provide specialist medical and nurse consultant advice to other providers throughout the Thames Valley Children's Palliative Care Network (see contact details below).

In developing this toolkit there is a strong recognition that there are many services that provide children's palliative care or respite services in the Thames Valley area. These may be provided by the NHS and Local authority or voluntary sector. There are also independent local projects.

Care provision can include:

→ respite care.	→ home care.	→ support groups.
→ day care.	→ clubs.	→ hospice care/hospice at home.

This section includes a list of services available in the Thames Valley Children's Palliative Network that provide services for children and young people. The information includes an outline of their referral criteria and their contact details. It is noteworthy that not all children who fulfil category 4 criteria will automatically be eligible for hospice care. In addition to the ACT guidance most hospices also have additional criteria that have to be met. Therefore referrers should check with individual hospices. It may be that children with these additional needs may qualify for community support from a different provider or will benefit from a different model of care.

We recognise that children you care for may come from a number of different counties where equivalent services are available. This section is concerned with Thames Valley and some closely linked services. You will need to check with your local provider for the full range of services available in areas such as Wiltshire, Northants & Bedfordshire. Please do note that organisations are going through a period of change so some of the details in the table below may alter.

Local authority support

Other useful links will include your local children’s social services and/or disabled children’s teams who can undertake assessments, make recommendations and present information to a multi-agency panel to decide what services would most appropriately meet the assessed needs. Help may include:

1	Referrals to other professionals such as psychologists or paediatric nurses
2	Support in the home or community
3	Occupational therapist assessment for equipment and/or adaptations
4	Respite breaks, either family based or residential
5	Holiday clubs
6	Liaison with education colleagues and schools
7	Support for disabled children transferring to adult services, to ensure a smooth transition and consistency of care.

Each county council and/or unitary authority will have a social work team, Special Educational Needs team and Learning Disabilities team for you to link with.

Bedfordshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
Keech Hospice Care	<p>Keech Hospice Care Great Bramingham Lane Luton Bedfordshire LU3 3NT</p> <p>T: 01582 492339 E: info@keech.org.uk W: www.keech.org.uk</p>	<p>♥ Provides specialist palliative care and support to families who have a child under the age of 19 years old with a life limiting condition within Milton Keynes, Bedfordshire and Hertfordshire.</p> <p>The purpose built 5 bedded hospice sits on the outskirts of Luton. Services include:</p> <ul style="list-style-type: none"> ♥ in-house hospice care for end of life care, symptom management, emotional support, transition from hospital stays and short breaks. There is a hydrotherapy pool. ♥ day care services offering play and stimulation five days a week for children who are not in full time education or out of school for a period of time. ♥ community nursing services, including 24 hour support for end of life care, symptom management, emotional and practical support. Liaison and professional support and advice. ♥ support and therapy services including a social worker, bereavement support staff, counselling, music and complementary therapist all of which can be offered within the hospice or family home if appropriate.

Berkshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>Children's Community Nursing Team</p>	<p>Berkshire NHS Foundation Trust – Paediatric Integrated Nursing Service (PINS) Craven Road Reading Berkshire RG1 5AN</p> <p>T: 0118 322 7532 F: 0118 322 8038</p>	<ul style="list-style-type: none"> ♥ Provides specialist nursing care for children their home, school or community setting. The service runs from 9am-5pm Monday to Friday service extending to 24/7 at end of life. The team includes: <ul style="list-style-type: none"> ♥ oncology nurse specialist. ♥ Cystic Fibrosis (CF) nurse specialist. ♥ Alexander's Home Care Nurse (AHCN) who offers short breaks and respite for families.
<p>Alexander Devine Outreach Nurse</p>	<p>Alexander Devine Outreach Nurse Pechiney House The Grove Slough Berkshire SL1 1QF</p> <p>T: 0845 055 8276 W: www.alexanderdevine.org</p>	<ul style="list-style-type: none"> ♥ Funds two Alexander Home Care Nurses who support families and children across Berkshire in their own homes, providing much needed respite, palliative care, emotional and practical support. ♥ Nurses support families at diagnosis and to lead on end of life care in the team. ♥ Referrals are via the Community Children's Nursing team at Royal Berkshire Hospital and Wexham Park Hospital – referrals will be widened to include East Berkshire.
<p>Ryeish Green Bungalow</p>	<p>Berkshire NHS Foundation Trust – Paediatric Integrated Nursing Service (PINS) Ryeish Green Bungalow Hyde End Lane Ryeish Green Reading Berkshire RG7 1ER</p> <p>T: 0118 988 2512 (Integrated Service Lead)</p>	<ul style="list-style-type: none"> ♥ A 3 bedded fully adapted respite unit. ♥ It offers residential respite care including over night stays and day care to children with complex health needs. There is a holiday club that runs Monday to Friday during the school holidays for this group of children. ♥ The service also provides a community respite service for children and young people with complex health needs, across the West of Berkshire, caring for children in their homes or any community setting. ♥ The service is staffed by qualified nurses and clinical support staff and nursery nurses. The resource has 3 residential beds, but can take up to 6 children during holiday club. ♥ Children need to be assessed through the Children's Continuing Care Panel. ♥ These services are available to children and young people under 18 years. ♥ The Integrated Paediatric Nursing Service also has close links with the school nurses working in the Special schools in West Berkshire: Addington (Wokingham), Avenue (Reading), Brookfields and Castle (West Berkshire).
<p>Castle Gate</p>	<p>T: 0163 542 400 (Team Manager)</p>	<ul style="list-style-type: none"> ♥ Provides short break provision for children and young people with Complex Health Needs, This is a joint health and social care provision and the social care part caters for children and young people with Learning Disabilities, Autism and Associated Behaviours. There are 2 health care beds. ♥ Offers day care, overnights and weekend respite, supports the families to continue caring for their child at home; providing education to carers to assist them in their role and to improve the child's management of needs where possible. ♥ Children need to be assessed through the Childrens Continuing Care Panel to access a health place. ♥ The service is available to children and young people under 18 years.

East Berkshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>East Berkshire Children's Community Nursing Team</p>	<p>Children's Community Nursing Room 39, Fir Tree House Upton Hospital Albert Street Slough Berkshire SL1 2BJ</p> <p>T: 01753 635017 E: CCNT@berkshire.nhs.uk</p> <p>Children's Respite Manor Green School Elizabeth Hawkes Way Maidenhead Berkshire SL6 3EQ</p> <p>T: 01628 501141 W: www.berkshire-eastchs.nhs.uk</p>	<p>Services for children and young people with complex health needs aged between 0-18 (19 years if in full time education). Children and young people may be seen by the service if they have a learning disability, learning difficulties or special needs and one or more of the following:</p> <ul style="list-style-type: none"> ♥ they require nursing and/or medical care. ♥ they require respite provision. ♥ they require continuing care assessment. ♥ they have been identified as in need of safeguarding. ♥ they have been referred by Medical Consultants, Paediatricians, GP's, Health Visitor, School Nurse or Social Services. <p>Children can be referred to the service by their consultant, GP, health visitor, school nurse, educational professional, social services or parent /carers.</p>
<p>Community Children's Nursing Team</p>	<p>Heatherwood and Wexham Park Hospitals NHS Foundation Trust Wexham Park Hospital Wexham Slough Berkshire SL2 4HL</p> <p>T: 01753 634617 F: 01753 634599</p> <p>'Reflections', a group for bereaved families. contact Jane Gates on E: info@sebastiansactiontrust.org T: 01344 622500</p>	<ul style="list-style-type: none"> ♥ Provides specialist nursing care for children their home, school or community setting. The service runs from 9am-5pm, 7 days a week <p>With service extending to 24/7 at end of life by 2 nurses. The team include:</p> <ul style="list-style-type: none"> ♥ oncology Advanced Nurse Practitioner (ANP). ♥ Cystic Fibrosis (CF) ANP. ♥ diabetic ANP. ♥ nurses who provide care for technically dependant children in the community setting ♥ Alexander's Home Care Nurse (AHCN) offers short breaks/ respite and end of life support for families. Ward based and community support also offered. ♥ there are good links with the local learning disabilities teams. ♥ 'Reflections' offer an annual service of remembrance and thanksgiving, a weekend away for bereaved families and opportunities to meet other bereaved parents and siblings. They meet families on a one to one basis or through family activities.

Buckinghamshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>Community Children's Nursing Service</p>	<p>Community Children's Nursing Service Stoke Mandeville Hospital Mandeville Road Aylesbury Buckinghamshire HP21 8AL</p> <p>T: 01296 315142</p>	<ul style="list-style-type: none"> ♥ Provides services for children with acute, chronic or palliative nursing care needs, who have a Buckinghamshire Paediatrician. ♥ Available 8am-6pm Monday to Friday. ♥ For end of life care only - available 24 hours per day.
<p>Children's Complex Care Service</p>	<p>Children's Complex Care Service Verney House Gatehouse Road Aylesbury Buckinghamshire HP19 8ET</p> <p>T: 01296 310032 or 01296 320012</p>	<ul style="list-style-type: none"> ♥ Assess children for continuing care packages.

continues overleaf

Buckinghamshire (continued)

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>Action for Children Short Break Centres and Outreach service</p>	<p>Action for Children Short Break Centres and Outreach service Merryfields Cressex Link High Wycombe Buckinghamshire</p> <p>The Grove Walton Street Aylesbury Buckinghamshire</p> <p>T: 01296 332600</p>	<ul style="list-style-type: none"> ♥ Short breaks for children with physical and/or learning disabilities, jointly funded by health and social care. ♥ Accessed via referral to social care.
<p>Florence Nightingale Hospice Florries Children's Team</p>	<p>Florence Nightingale Hospice (Florries Children's Team) Stoke Mandeville Hospital Aylesbury Buckinghamshire HP21 8AL</p> <p>T: 01296 394710</p>	<ul style="list-style-type: none"> ♥ Provides specialist palliative nursing care to children, young people (aged 0-19 years) and their families in their own home. ♥ Care is provided to children and young people with life-limiting and life-threatening conditions. ♥ Advice and support is available 24/7 at end of life. ♥ Care includes short breaks at home, symptom management, advice and support for siblings and end of life care. ♥ The team also has 24/7 access to specialist medical advice and support via Helen and Douglas House and work closely with all professionals involved with the child.
<p>Iain Rennie Grove House Hospice Care Pepper Children's Team</p>	<p>Iain Rennie Grove House Hospice Care (Pepper Children's Team) 52a Western Road Tring Hertfordshire HP23 4BB</p> <p>T: 01442 890444</p> <p>9am-5pm Monday to Friday (answer machine outside these hours)</p> <p>E: nursing@irhh.org W: www.irhh.org</p>	<ul style="list-style-type: none"> ♥ Covering the Chilterns district of Hertfordshire and Buckinghamshire, the IRGH Pepper Children's Team provides specialist palliative nursing care to children, young people (aged 0-19 years) and their families in their own home. ♥ Care is provided to children and young people with life-limiting and life-threatening conditions and advice and support is available 24/7 through an on call service. ♥ Care includes short breaks at home, symptom management advice and end of life care. ♥ The team also has 24/7 access to specialist medical advice and support via Helen & Douglas House and work closely with all professionals involved with the child.
<p>Paediatric Acute Community Team Milton Keynes</p>	<p>Paediatric Acute Community Team Milton Keynes Foundation Hospital Standing Way Eaglestone Buckinghamshire MK6 5LD</p> <p>T: 01908 660033 ext 2703</p> <p>8.30am-4.30pm Monday to Friday 9am-12pm Saturday</p>	<ul style="list-style-type: none"> ♥ Available for children up to the age 16 years old. ♥ Covering Milton Keynes area. ♥ Team is caring for acute and long term conditions. ♥ Children with cancer and blood disorders, nephrotic syndrome etc. ♥ Facilitating discharge from hospital. ♥ Supporting parents caring for their sick child at home. ♥ School support. ♥ The team could work alongside with local Complex Need Team and Keech Cottage if end of life is needed for a family.
<p>Bereaved Parent Support Group Milton Keynes</p>	<p>Group facilitated by children's community nurses</p> <p>T: 01908 660033 ext 2703 E: mkbereavedparentsgroup@hotmail.co.uk</p>	<ul style="list-style-type: none"> ♥ Group meets every third Thursday of the month at a local family centre 7.30pm-9.30pm. Any parent who lost a child of any age is welcome.

Hampshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>Naomi House and jacksplace hospices for children and young adults</p> <p>Central Southern England</p>	<p>Naomi House Stockbridge Road Sutton Scotney Winchester Hampshire SO21 3JE</p> <p>T: 01962 760060 W: www.naomihouse.org.uk</p> <p>Referrals via the Care Team</p> <p>T: 01962 760 555 E: care@naomihouse.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides a 24/7 Palliative Care Service for families whose children and young adults have a life limiting illness and life threatening illness, from Central Southern England. Which includes planned and unexpected respite care, short breaks, day visits, end of life care and support; Bereavement Support and Family/Sibling Support and Emergency End of Life hospice at home care. ♥ Naomi House and jacksplace accept referrals for babies, children and young adults, up to the age of 25, who have life limiting or life threatening conditions and require palliative care and support. Referrals will be considered for individuals from across the central south including the counties of Berkshire, Dorset, Hampshire, Isle of Wight, Surrey, Sussex and Wiltshire. For young adults who are referred from outside the area statutory funding to support their referral will be required. ♥ Referral criteria – a child/young person’s condition(s) must fall within the guidelines issued by ACT.

Oxfordshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>Community Children’s Nursing Service</p>	<p>Community Children’s Nursing Service ISIS Business Centre Unit 1 Pony Road Cowley Oxfordshire OX4 2RD</p> <p>T: 01865 402700 F: 01865 402701 E: ccnteam@oxfordhealth.nhs.uk W: www.oxfordhealth.nhs.uk</p>	<p>The Children’s Community Nursing Service includes:</p> <ul style="list-style-type: none"> ♥ children’s community nurses. ♥ children’s respite nurses. ♥ clinical nurse specialists in special schools. ♥ shared care protocols training co-ordinator. ♥ community play specialist. ♥ community children’s nurses and respite nurses deliver continuing care packages. ♥ accept children with acute chronic or palliative nursing care needs, who’s GP belongs to Oxon PCT. ♥ respite care is available Monday to Friday 9am-5pm with occasional week day evenings. Sessions are normally three hours in duration, weekly or fortnightly for children in Oxfordshire. ♥ 8am-6pm Monday to Friday, 9am-5pm Saturday and Sunday. Available 365 days per year.
<p>Children’s Complex Care Service</p>	<p>Children’s Complex Care Service East Oxford Health Centre Manzil Way Cowley Oxford</p> <p>T: 01865 265025 E: ChildrensComplexCare@oxfordhealth.nhs.uk W: www.oxfordhealth.nhs.uk</p>	<ul style="list-style-type: none"> ♥ Work closely with partner agencies, local health providers, families and carers to ensure appropriate health provision is available for children with a wide variety of complex needs. ♥ Provides case management and Continuing Health Care assessments. ♥ The process of assessment begins within 48 hours of a 5 day working week.

continues overleaf

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
<p>ROSY <i>(Respite nursing for Oxfordshire's Sick Youngsters)</i></p>	<p>ROSY 80 Evans Lane Kidlington Oxford OX5 2JA</p> <p>T: 01865 848696 (not for referrals) E: help@rosy.org.uk W: www.rosy.org.uk</p>	<ul style="list-style-type: none"> ♥ Under the umbrella of the Oxfordshire Primary Care Trust Charity provides additional respite care to Oxfordshire's sick youngsters who are nursed at their own homes. ♥ Services include nursing, medical and sensory equipment and specialist toys, a limited counselling service and assistance to support a leisure facility for the sick youngsters and their siblings. ♥ Referrals are via the Community Children's Nursing Service on 01604 545517.
<p>Paediatric Oncology Outreach Nurse Specialists</p>	<p>Oxford Radcliffe Hospitals NHS Foundation Trust Paediatric Oncology Department Level 2 The Children's Hospital John Radcliffe Hospital Headley Way Headington Oxford OX3 9DU</p> <p>T: 01865 234988</p>	<ul style="list-style-type: none"> ♥ The team provides home care for children diagnosed with a malignancy, including those children who require palliative and end of life care. ♥ 24 hour advice is available on a pre-arranged basis for families of children receiving palliative and end of life care. ♥ The service runs from 8am-6pm Monday to Friday. The team includes two paediatric oncology outreach nurse specialists covering Oxfordshire.
<p>Barnados Short Break Centres</p>	<p>Barnados Short Break Centres Viking House Saxon Way Headington Oxford OX3 9DD</p> <p>Sycamore Resource Centre 66 Oxford Road Banbury Oxfordshire OX16 9AN</p>	<ul style="list-style-type: none"> ♥ Viking House (Oxford) is a residential unit offering short break care to children with a wide range of disabilities. The service is managed by Barnardo's, but commissioned by Oxford PCT and Oxfordshire County Council. ♥ Sycamore Resource Centre (Banbury) is a 5 place residential unit offering short break care to children with a range of disabilities and some complex health needs. ♥ Barnardo's work in partnership with Oxford PCT and Local Authority. ♥ Accessed via referral to social care.
<p>Helen & Douglas House</p>	<p>Helen & Douglas House 14A Magdalen Road Oxford OX4 1RW</p> <p>T: 01865 794749 F: 01865 20270 W: www.helenanddouglas.org.uk</p>	<ul style="list-style-type: none"> ♥ Provides respite, emergency admissions for symptom control or end of life care for children and young people aged 0-35 years with life limiting conditions. ♥ Specialist medical advice to other providers. ♥ Nurse consultant out reach/specialist support. ♥ Office hours 9am-5pm Monday to Friday.

Wiltshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
Community Children's Nursing Team	Great Western Hospitals NHS Foundation Trust Great Western Hospital Marlborough Road Swindon Wiltshire SN3 6BB T: 01793 604020 Direct Line: 01793 604969	A team of specially trained nurses who care for children and their families in Swindon, both at home and in the wider community. The team offers: <ul style="list-style-type: none"> ♥ Feeding management including assistance with nasogastric/gastrostomy feeding. ♥ Care and monitoring of children requiring oxygen therapy. ♥ Post operative nursing care. ♥ Monitoring and administration of medication and intravenous medicines. ♥ Palliative care and symptom control. ♥ Care for children with complex health needs. ♥ Specialist nursing care for children with cancer, diabetes and cystic fibrosis.
The Saltway Children's Centre Children's Continuing Care Team	Integrated Service for Disabled Children Children Services Salt Way Centre Pearl Road Swindon Wiltshire SN5 5TD T: 01793 464240 W: www.swindon.gov.uk/el/el-integrateddisabledchildren	<ul style="list-style-type: none"> ♥ Provides care to children who have a complex health need or who are technology dependent i.e. ventilation and tracheotomies. ♥ Offers high level care needs, specialist assessment multi-agency care package for children with multiple needs or in need of immediate care and protection ♥ Referrals accepted from professional in health, social care and education services locally or through health care teams elsewhere in the country. ♥ Children need to be assessed through the continuing care panel.

Northamptonshire

RESOURCE	CONTACT INFORMATION	REFERRAL INFORMATION
Children's Outreach Nurses	Northampton General Hospital NHS Trust Children's Outreach Nurses Cliftonville Northampton NN1 5BD T: 01604 545517 or 01604 523896 9am-5pm Monday to Friday and emergency telephone advice at weekends W: www.northamptongeneral.nhs.uk	<ul style="list-style-type: none"> ♥ Available for children (up to aged 18-19 years in full time education) and families who require a high degree of technical intervention and medical support, children with life threatening or life limiting conditions and those who may require palliative or terminal care. ♥ Support and care is given to children and young people with chronic/life limiting/threatening conditions covering areas such as: Diabetes, Cystic fibrosis, Epilepsy, Childhood cancer and blood disorders, Continuing care at home, Palliative care, Support for children who are oxygen dependent, enterally fed, use of suction and help with tracheotomies, asthma. ♥ The team consist of specialist nurses in childhood cancers and blood disorders, Epilepsy nursing and Children's Community Nursing. ♥ The team also provide bereavement support, information and advice.
Child & Adolescent Bereavement Service	Child & Adolescent Bereavement Service Northampton General Hospital Cliftonville Northampton NN1 5BD T: 01604 545131 F: 01604 544554	<ul style="list-style-type: none"> ♥ Offers support to parents, carers, school staff or any agency caring or working with a bereaved child or adolescent. ♥ Also offer support to families where a member has a terminal illness. ♥ Training can be provided to schools and agencies.

Training tools

There are a variety of training tools that can be used by clinicians to develop their own practice and to develop the quality of the services they provide.

Below are some tools that are suitable for registered nurses and unregistered practitioners.

Oxfordshire Shared Care Protocols (also used in other counties for training for delegated tasks)

The Shared Care Protocols were developed as training protocols for sharing care of children in any setting across disciplines and agencies in a safe and accountable manner. The aim of the protocols is to ensure that all care workers are trained to a high standard so children receive a consistent level of care from competent staff. Each care task identified will be categorised into one of five levels of training.

Level 1 and 2

The care worker will have received general, basic training from their employer and/or health care professional. These are transferable skills. Level 2 tasks are classified to meet a health need.

Level 3 and 4

These are health care tasks and require a specific care worker to receive training for a "named" child from a health care professional. They must be assessed as competent to undertake the task and documentation be signed by the health professional to indicate this. At the time of assessment of competence monitoring and training update will be agreed. Level 4 are perceived as complex and complicated health care tasks.

Level 5

These tasks can only be carried out by a health care professional; a care worker cannot undertake them. Parents must be offered training by a health care professional so that they can feel confident, competent and adequately supported so that they can care for their child at home.

Other Tasks

Some tasks will require bespoke care plans and training so have not been included specifically. Clarification about any task should involve contacting the Community Children's Nursing Team.

Source: Oxfordshire and Buckinghamshire Shared Care Protocols (accessed 9th August 2011)

ACT training tools

Nurses in Coventry and Warwickshire PCTs developed a number of electronic tools to support staff who care for children and young people with complex health needs. These tools include competency frameworks, PowerPoint presentations, workbooks and teaching aids in areas of related to general nursing care and palliative care for children. Information can be downloaded from:

→ www.act.org.uk/page.asp?section=113§ionTitle=Coventry+and+Warwickshire+Children+and+Young+People%27s+Teaching+Framework

Children's Hospice UK

The Children's Hospice UK also provide access to competencies, professional toolkits and work books including:

Benchmarks

→ www.childhospice.org.uk/system/search-results?query=benchmark

Diversity Toolkit

→ www.childhospice.org.uk/media/64454/the%20diversity%20toolkit.pdf

Medicines Management in a Hospice Settings Toolkit

→ www.childhospice.org.uk/media/64388/medicines%20management%20toolkit.pdf

Competencies and Work Books to Develop Skills in Ventilation

→ www.childhospice.org.uk/system/search-results?query=ventilation

Royal College of Nursing resources

The Royal College of Nursing have a forum for nurses working with children and young people with palliative care needs. The forum supports and advises all members who provide palliative care inclusive of all care settings, from point of care through to bereavement support.

→ www.rcn.org.uk/development/communities/rcn_forum_communities/children_and_young_people_field_of_practice/cyp_continuing_care/cyp_palliative_care_community

The RCN have a number of resources for non registered health care professionals, including a toolkit, which can be found at:

→ www.rcn.org.uk/development/health_care_support_workers/learning_and_development/hca_toolkit

(accessed 4th August 2011)

For further RCN resources on accountability and delegation visit:

→ www.rcn.org.uk/hcaaccountability

There is also advice from the NMC (2008) that relates to the Code: standards of conduct, performance and ethics for nurses and midwives.

→ www.nmc-uk.org/Nurses-and-midwives/Advice-by-topic/A/Advice/Delegation

For the link below you will need to be a member of the RCN, have a membership number and a log in password.

→ www.rcn.org.uk/support/rcn_direct_online_advice/nursing_practice/health_care_assistants/health_care_assistants_-_delegation_and_accountability/what_roles_can_a_hca_carry_out

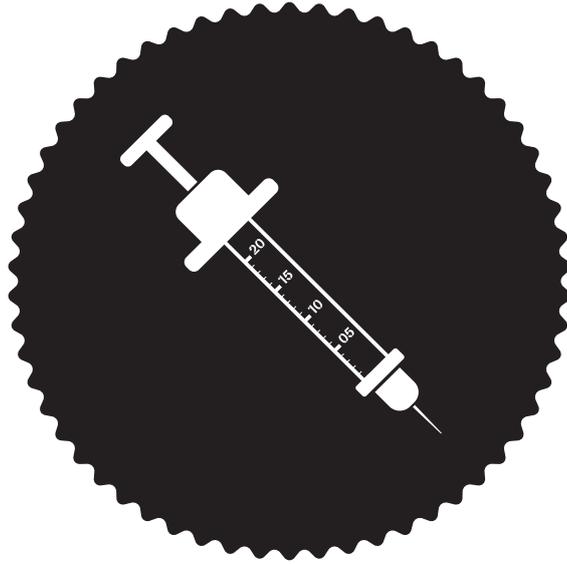
(accessed 4th August 2011)

West Midlands Palliative Care Toolkit

A more in-depth toolkit has been developed by West Midlands Paediatric Palliative Care Steering Network who was similarly successful in gaining Department of Health funding. The toolkit complements the Thames Valley version by including similarly resources in greater depth and includes information such as:

→ planning and managing children's palliative care.	→ advanced care planning information, including a policy and what to do.
→ caring for children and families at the time of death.	→ the Rainbows symptom control manual.
	→ APPM Master Formulary.

→ www.act.org.uk/page.asp?section=417§ionTitle=West+Midlands+Children+and+Young+People%27s+Palliative+Care+Toolkit



Medication

- 47 Commonly used medication**
- 48 Pain assessment**
- 49 Pain management**
- 50 Routes of administration**
 - Side effects of opioids**
- 51 Alternatives to morphine**
 - Neuropathic pain**
- 52 Nausea and vomiting**
 - Constipation**
 - Seizure**
 - Agitation, sedation and terminal restlessness**
- 54 Dyspnoea**
- 55 Noisy breathing**
- 56 Distraction techniques in Children**

Children's palliative care medication

This section looks at the commonly used medication and treatments for a range of symptoms that may occur at the end of a child or young person's life.

A key reminder underpinning this section is for clinicians to assess individual symptoms on individual merit and always consider the normal/obvious (e.g. colic) causes of pain, where possible prior to commencing treatment.

Commonly used medication

Management of pain is frequently complex and involves a number of medications. The key principles that support effective pain management are advised by the World Health Organisation (WHO). For its best effect medication should be given:

- 1 **By mouth** – that is oral medication
- 2 **By the clock** – preventative regular medication
- 3 **By the ladder** – the WHO pain ladder (see overleaf)

My life would be easier if... 'there were nurses who could look after me at home rather than having to go into hospital.'

Department of Health (2008) Better Care: Better Lives

Pain assessment

Pain Assessment requires an appropriate knowledge of the individual patient as well as the family and an appreciation of stages of the patient’s cognitive development. Useful approaches to assessment include:

ASSESSMENT SOURCE	INFORMATION REQUIRED
Parent/carer	♥ Advise parent what to observe in their child’s condition over a 24 hour period and how to keep record of analgesia given and its effects.
Behaviour of child	♥ Assess mood (e.g. crying, quietness), facial expression, rigidity, guarding, body movement.
Psychological, social and cultural factors	♥ Gain wider information concerning awareness of disease status/progression, depression, environment, religious/cultural beliefs.
Self report	♥ Use tools with the child such as faces scale, visual analogue scales, numeric, pain diaries.

Source: World Health Organisation www.wpro.who.int/nr/rdonlyres/8027fb53-aac8-4cb4-a5a1-1b149af0c455/0/etatmanualforparticipants.pdf (accessed 24th July 2011)

The Paediatric Pain Profile (PPP)

The Paediatric Pain Profile (PPP) is a behaviour rating scale for assessing pain in children with severe physical and learning impairments. www.pppprofile.org.uk

“Severe physical and learning impairment is a feature of many chronic and disabling conditions in children. These children have many potential sources of pain. Pains may arise from the disease process itself (e.g. neuropathic pain or muscle spasm), be secondary to the disease (e.g. musculo-skeletal pain or pain from reflux oesophagitis) or incidental (e.g. tooth ache or otitis media). However, because the children have difficulty in communicating their pain it can go unrecognised and untreated. It is the child’s behaviour often, rather than their verbal report, which has to be interpreted to determine if they have pain.”

Hunt, A. – Paediatric Pain Profile www.pppprofile.org.uk (accessed 24th July 2011)

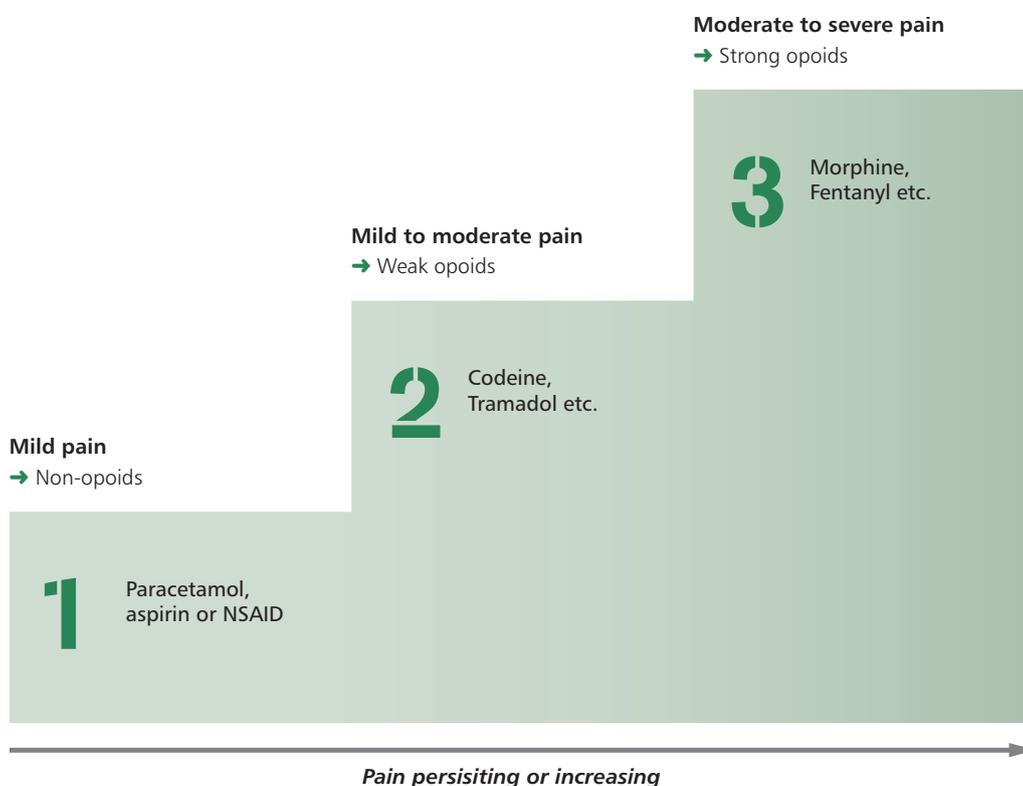
Pain management

The World Health Organisation (WHO) developed guidelines to describe a 3 step analgesic ladder (see below). WHO states:

“If pain occurs, there should be prompt oral administration of drugs in the following order: non-opioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – ‘adjuvants’ – should be used. To maintain freedom from pain, drugs should be given ‘by the clock’, that is every 3-6 hours, rather than on demand.”

Source: www.who.int/cancer/palliative/painladder/en/ (accessed 13th May 2011)

STEP	PAIN TYPE	ANALGESIA
1	Mild Pain Non-opioids	<ul style="list-style-type: none"> ♥ Paracetamol, maybe useful with opioids for bone pain. ♥ NSAIDS (Ibuprofen/ Diclofenac), useful for bone metastases and soft tissue inflammation. ♥ May need to give anti-emetics for gastric protection.
2	Mild to moderate pain Weak opioid	<ul style="list-style-type: none"> ♥ Codeine phosphate – constipation should be anticipated, prescribe laxative. ♥ Maybe useful to control headaches related to raised intracranial pressure.
3	Moderate to severe pain Strong opioids	<ul style="list-style-type: none"> ♥ Morphine, Oxycodone, Fentanyl. ♥ Oral morphine is the drug of choice in the majority of opioid naïve children with severe pain.



Routes of administration

ROUTE	INDICATION
Oral or enteral	♥ The route of choice if the child is able to take orally and/or absorb enterally.
Subcutaneous infusion	♥ Dysphagia, persistent vomiting, bowel obstruction, patient too weak to take oral meds, unsatisfactory response to oral medication, practical administration problems with other routes.
Intravenous (IV)	♥ This route of administration would only be used if central venous access is available.
Sublingual/ transmucosal	♥ E.g. fentanyl lozenges, Rapid onset of action (approx 5 minutes) and short duration (up to 2 hours). The lozenge should be rubbed gently against the oral mucosa.
Buccal	♥ Buccal morphine is useful for rapid relief of sudden onset or rapidly escalating pain, dose 1/3rd - 1/5th oral breakthrough dose (use IV preparation) and apply between cheek and the gingiva. Useful alternative if patient too ill to tolerate fentanyl lozenges.
Transdermal	♥ Good for stable pain, change patch every 3 days (7 days for Buprenorphine). Once patch started continue oral preparation for 12-24 hours before stopping. Prescribe oral or buccal breakthrough doses. The drug will stay in circulation for up to 30 hours after patch has been removed.
Epidural/intrathecal	♥ Maybe indicated in chronic pain and for intractable pain where it may produce effective analgesia with much smaller doses of opioid and therefore fewer side effects. This method of administration should only be considered with the help of a suitably experienced anaesthetist.

Source: Adapted from Harrop, E. & Parks, H (2011)

Side effects of opioids

SIDE EFFECT	MANAGEMENT
Drowsiness	♥ Usually improves after a few days. ♥ Consider lowering dose.
Constipation	♥ Co-prescribe a laxative (prescribe combined stimulant and softener combination).
Urinary retention	♥ Consider potential causes (exclude spinal cord compression). ♥ Try simple measures; sit in warm bath, treat constipation, rotate opioid, catheterisation.
Nausea	♥ Usually settles after 5-7 days, may need anti-emetic such as cyclizine.
Confusion	♥ Confusion/hallucination/nightmares – often settles, opioid rotation may help, may be treated with haloperidol.
Itching	♥ Good skin care, chlorpheniramine, ondansetron, cimetidine.
Respiratory depression	♥ Naloxone.
Opioid toxicity	♥ Signs – increased drowsiness, confusion, myoclonic jerks, hallucinations. <i>Can occur with:</i> → too higher a dose - may need to omit a dose, and then restart at lower dose. → too rapid dose escalation. → pain unresponsive to opioid - Consider opioid switch. → renal impairment - reduce dose to 75% in mild to moderate renal failure, and 50% or less in severe renal failure, consider prescribing 6-8hrly or only as PRN. Consider changing to fentanyl/alfentanyl.

Source: Adapted from Harrop, E. & Parks, H (2011)

Alternatives to Morphine

Oxycodone	<ul style="list-style-type: none"> ♥ Less itching/sometimes less hallucinations.
Fentanyl (alfentanyl)	<ul style="list-style-type: none"> ♥ Useful in renal failure and can be used as transdermal patch and as lozenges (transmucosal).
Methadone	<ul style="list-style-type: none"> ♥ Maybe useful for neuropathic pain. ♥ Must be used only after recommendation by palliative care consultant.
Diamorphine	<ul style="list-style-type: none"> ♥ Used in pain of all types unless opioid insensitivity shown. ♥ Can be titrated from previous opioid.

Source: Adapted from Harrop, E. & Parks, H (2011)

Neuropathic pain

Maybe caused by compression, direct invasion, metabolic disturbance to or infection of nervous tissue. It manifests as altered sensation and maybe described by the patient as burning, shooting, tingling, or pins and needles. Neuropathic pain is likely to be partially opioid resistant, and therefore opioids maybe supplemented with adjunctive analgesics such as:

DRUG	NOTES
Amitriptyline	<ul style="list-style-type: none"> ♥ Analgesic properties of this drug occur independently of its mood altering effects, at lower plasma concentrations, and at an earlier onset of treatment (3-5 days after starting). Its use maybe limited by its anti muscarinic effects, sedation, lowering seizure threshold, cardiac arrhythmia and hypotension.
Gabapentin	<ul style="list-style-type: none"> ♥ Is an anticonvulsant licensed in adults for management of neuropathic pain. Capsules can be opened and contents given in strong flavoured drink i.e. blackcurrant /cola.
Ketamine	<ul style="list-style-type: none"> ♥ Use only with advise from a specialist palliative care team. ♥ All co-analgesic drugs should be slowly reduced if the ketamine is successfully treating the pain. ♥ Can cause hallucinations/nightmares in older children, which may be helped by haloperidol, diazepam/lorazepam, or midazolam. Caution in children with pulmonary hypertension as may cause elevation of BP and pulse. May cause laryngospasm in infants.
Methadone	<ul style="list-style-type: none"> ♥ May have role in controlling neuropathic pain.
Clonazepam	<ul style="list-style-type: none"> ♥ Use only with advice form specialist palliative care team.

Source: Adapted from Harrop, E. & Parks, H (2011)

Gastro intestinal symptoms

Nausea and Vomiting

Consider possible cause:

1 Raised intracranial pressure (ICP).	6 Gastric irritation.
2 Pain/Anxiety.	7 Cough.
3 Chemotherapy/radiotherapy.	8 Uraemia.
4 Other drugs (opioid).	9 Intercurrent illness (e.g. UTI).
5 Constipation/obstruction.	

General measures:

- Remove/treat cause if possible.
- Avoid strong smells.
- Keep meals small/remove left over food promptly.
- Minimise anxiety provoking situations (i.e. good analgesia for incident pain).

CAUSE	DRUG OF CHOICE
Chemotherapy	♥ Metoclopramide, Ondansetron, Cyclizine, Dexamethazone, Aprepitant.
Raised intracranial pressure	♥ Cyclizine, Dexamethazone.
Partial gastric outlet obstruction	♥ Metoclopramide, Domperidone.
Complete gastric obstruction	♥ Hyoscine, Octreotide.
Anticipatory	♥ Benzodiazepines, cannabinoids, Levopempromazine.
Anxiety/agitation	♥ Levopemromazine.

Source: Adapted from Harrop, E. & Parks, H (2011)

Constipation

Consider underlying cause and treat when possible:

1 Inactivity, weakness, poor food and fluid intake and debility.
2 Metabolic – dehydration, hypercalcaemia, hypokalaemia.
3 Drugs such as opioids, vincristine.
4 Cord compression, cauda equina syndrome.
5 Obstruction.

Management (constipation)

DRUG	MODE OF ACTION	NOTES
Lactulose	Osmotic laxative	<ul style="list-style-type: none"> ♥ Onset of action up to 48 hours. ♥ Needs to be prescribed regularly. ♥ May cause flatulence, cramps, abdominal discomfort. Osmotic mode of action therefore encourage oral intake.
Senna	Stimulant	<ul style="list-style-type: none"> ♥ Onset of action 6-12 hours. ♥ Prescribe initial dose to avoid 'gripping'. ♥ Works well in combination with docusate or lactulose if stimulant and softener required.
Docusate	Softener and mild stimulant	<ul style="list-style-type: none"> ♥ Onset of action 1-2 days if taken regularly.
Bisacodyl	Stimulant	<ul style="list-style-type: none"> ♥ Onset of action 10 to 12 hour for tablets or 20 to 60 minutes for suppositories. ♥ Works well in combination with docusate or lactulose if stimulant and softener required.
Movicol	Osmotic/bulking	<ul style="list-style-type: none"> ♥ Use for chronic constipation or impaction. ♥ Avoid in intestinal obstruction.

Source: Adapted from Harrop, E. & Parks, H (2011)

RECTAL PREPARATIONS (Avoid in neutropenic /thrombocytopenic patients)	
Phosphate/microlax enema	♥ Use for rectal impaction.
High arachis oil enema (softener)	♥ Be aware of nut allergies as this product is made from peanuts.

Source: Adapted from Harrop, E. & Parks, H (2011)

Seizure

For emergency control of seizures buccal midazolam is the treatment of choice.

For palliative control of seizures subcutaneous infusion of midazolam (or phenobarbitone) is used.

Agitation, sedation and terminal restlessness

Exclude treatable causes of agitation:

1 Uncontrolled pain.	5 Muscle spasm.
2 Reflux, constipation, gastric irritation.	6 Hypoxia.
3 Urinary retention.	7 Raised ICP.
4 Drugs e.g. Ketamine.	8 Fear, anxiety, environmental factors.

continues overleaf

DRUG	NOTES
Midazolam	<ul style="list-style-type: none"> ♥ The sedative of choice. ♥ Can be mixed with other commonly used drugs in a syringe driver. ♥ Low doses by continuous infusion are useful for relieving agitation. ♥ Increase dose gradually in <i>small</i> increments according to response.
Levomepromazine	<ul style="list-style-type: none"> ♥ Use of anti-emetic also required. ♥ Very sedating so start at lower dose ♥ May lower seizure threshold.
Haloperidol	<ul style="list-style-type: none"> ♥ Useful as long acting, once daily dose often adequate. ♥ Not licensed for nausea and vomiting, restlessness and confusion or intractable hiccups.
Lorazepam	<ul style="list-style-type: none"> ♥ Short acting/quick onset. ♥ Well absorbed sublingually. ♥ Good for panic attacks.

Source: Adapted from Harrop, E. & Parks, H (2011)

Respiratory symptoms (dyspnoea)

Identify and treat cause if possible:

1 Pulmonary – metastases, effusion, infection, fibrosis, Pulmonary Embolus (PE).	4 Anaemia.
2 Chest wall pain/constriction.	5 Cardiac failure.
3 Superior vena cava (SVC) obstruction.	6 Enlarged liver.
	7 Increased secretions.
	8 Anxiety/fear.

TREATMENT	NOTES
General measures	<ul style="list-style-type: none"> ♥ Explain to child and parents. ♥ Play therapy. ♥ Fan/window open. ♥ Relaxation therapy. ♥ Breathing exercises. ♥ Position change.
Nebulised therapy	<ul style="list-style-type: none"> ♥ B2, Ipratropium, steroid.
Oxygen/Heliox	<ul style="list-style-type: none"> ♥ Use is controversial, but some children may benefit. ♥ Mask may not be tolerated consider nasal prongs.
Morphine	<ul style="list-style-type: none"> ♥ At 30-50% of analgesic dose, can use buccal route. ♥ Regular oramorph or MST may be needed.
Diazepam	<ul style="list-style-type: none"> ♥ Has anxiolytic and sedative effects, also relaxes the respiratory muscles.
Midazolam	<ul style="list-style-type: none"> ♥ Buccal dose as for anxiety.

Source: Adapted from Harrop, E. & Parks, H (2011)

Noisy breathing

At end of life noisy breathing rarely upsets the child, but maybe very distressing for the relatives. This needs to be carefully explained to parents.

It is unusual to need any of the following drugs:

DRUGS	NOTES
Glycopyrronium	<ul style="list-style-type: none">♥ Anticholinergic, reduced the pharyngeal secretions.♥ Maybe used while the patient remains conscious as does not cross the blood brain barrier.
Hyoscine hydrobromide	<ul style="list-style-type: none">♥ Anticholinergic, reduced the pharyngeal secretions, but crosses the blood brain barrier.♥ May cause drowsiness, restlessness, disorientation or confusion.
Hyocine patch	<ul style="list-style-type: none">♥ Easy to apply. If commencing an infusion and patient already has a patch, the patch should be removed prior to infusion starting.

Source: Adapted from Harrop, E. & Parks, H (2011)

Palliative care box

It is likely you will find it helpful to develop a palliative care box when faced with a situation in which a child or young person deteriorates. This box will need to include some of the main medications and/or dressings that may be needed at the end of life. A list can be available on www.rcn.org.uk and search for Vickers, J. document identification number [pdf_file/0009/270873/4.7.2](http://www.rcn.org.uk/data/assets/pdf_file/0009/270873/4.7.2)

→ www.rcn.org.uk/data/assets/pdf_file/0009/270873/4.7.2_palliative_care_drug_boxes.pdf (accessed on 4th August 2011)

Advice about end of life symptom management should be obtained from your identified specialist in children's palliative care.

Suggested reading

More detailed information and dose advice can be found in the following texts.

ACT (2011) Basic Symptom Control in Paediatric Palliative Care

The Rainbow Children's Hospice guidelines (Eighth Edition)

→ www.act.org.uk/symptomcontrol

Association for Paediatric Palliative Medicine (APPM) formulary for paediatric palliative medicine

→ www.act.org.uk/appmformulary

British National Formulary for Children provides healthcare professionals with information on the use of medicines for treating children.

→ www.bnfc.org/bnfc

Non pharmacological interventions

Distraction techniques in children

AGE (YEARS)	METHODS
0 - 2	♥ Touching, stroking, patting, rocking, playing music, using mobiles over the cot.
2 - 4	♥ Puppet play, storytelling, reading books, breathing, blowing bubbles.
4 - 6	♥ Breathing, storytelling, puppet play, talking about favourite places, TV shows, activities.
6 - 11	♥ Music, breathing, counting, eye fixation, thumb squeezing, talking about favourite places, activities on TV shows, humour.

Source: www.childcancerpain.org/content.cfm?content=nonphar03 (accessed 4th June 2011)

There are a range of distractions and therapies which may include:

- play therapy.
- music therapy.
- complementary therapies.
- heat packs.



Planning

59 Anticipating a child's palliative care journey

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Care support and information for a family once their child has died

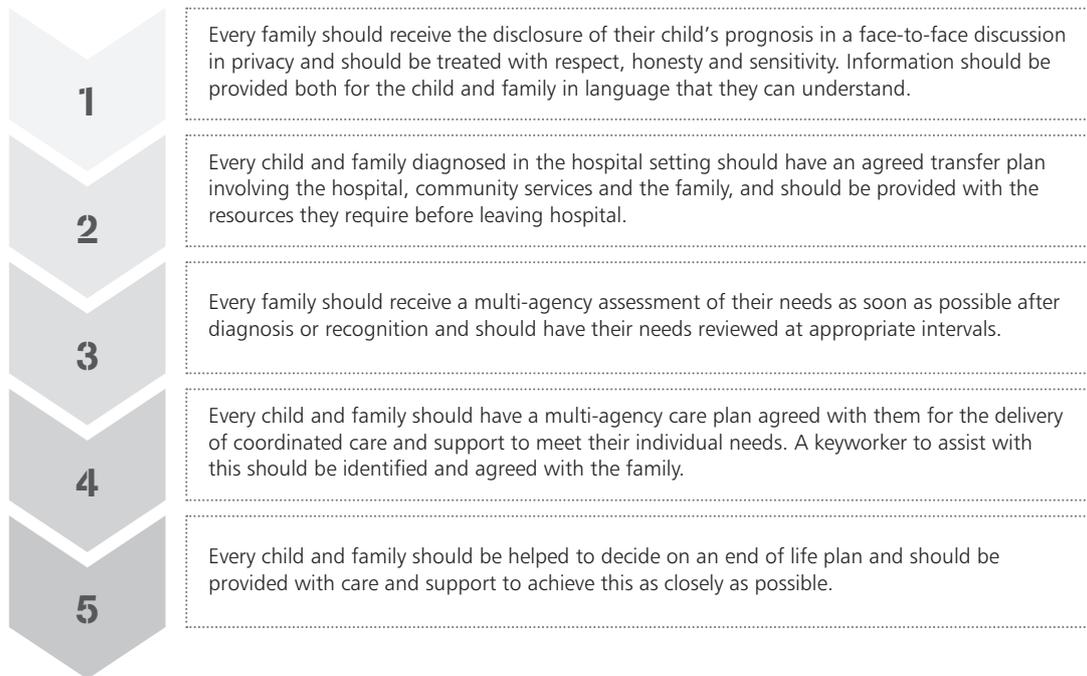
63 Consideration of religious and cultural practices

64 Looking after staff working with children who have palliative care needs

Looking after yourself

Further reading

Anticipating a child's palliative care journey



Source: ACT (2004) Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting conditions. www.act.org.uk/page.asp?section=114§ionTitle=ACT%27s+care+pathway+for+children

Choices for end of life care may include:

→ home supported by community children's nursing services and specialist palliative care services.	→ hospital.
→ children's or young person's hospices.	→ a combination of the above.

"The needs of children requiring palliative care are in many cases such that they dip in and out of services according to their condition at the time."

Craft and Killen (2007: p.15)

Most families would prefer not to die in hospital; however, in 2007 Craft and Killen identified that three quarters of children did die in hospital. It can often be difficult to predict a child's phase of illness and this can be characterised with fluctuating conditions or a rapid deterioration.

Ensuring a smooth transition to their place of choice, home or hospice, to support a child dying is paramount and involves:

<ul style="list-style-type: none"> → practical issues such as organising transport or sorting out medication. 	<ul style="list-style-type: none"> → social issues such as organising relevant services and means of communication amongst services and with the family or child/young person.
<ul style="list-style-type: none"> → psychological issues such as planning for deterioration or a pattern of improvement and deterioration. 	<ul style="list-style-type: none"> → spiritual or pastoral support for parents, siblings and the child or young person.

Supporting a child's palliative care journey



Annie was a five year old with a complex genetic brain abnormality. She had multiple operations on her brain and was well in between surgery. She made good developmental progress. Annie had some physical disabilities which were managed with minimal community intervention.

Annie developed raised intracranial pressure and further surgery was less effective and she did not recover fully. Following lengthy conversations between her parents, the surgeon and ward staff a decision was made to cease active surgical intervention. Annie, however still had signs of raised intracranial pressure which needed to be managed. Annie's parents agreed to look at hospice care as the next step for Annie.

Annie arrived at the hospice for assessment and the development of a symptom management plan. It was not clear whether or not she would have end of life care at the hospice and what the time scales of any deterioration would be.

Annie and her parents settled into hospice life very quickly. They appreciated the care and nurturing for themselves which allowed them time to come to terms with the withdrawal of active treatment for Annie and started to decide what their wishes for end of life care would be. Annie enjoyed some brief time in the garden and sensory rooms before her symptoms prevented further active engagement. A comprehensive symptom management plan encompassed pain relief for the pain of raised intracranial pressure, anti-convulsant

medication to control increasing seizure activity, medication to reduce anxiety and also possible nausea. Medication was given via naso-gastric tube and syringe driver. Annie was also fed via her naso-gastric tube to maintain nutrition and hydration. Although her oxygen saturations were satisfactory Annie was more settled with continuous low flow oxygen via nasal cannulae. Only minimal monitoring of Annie was undertaken as her parents and hospice staff were confident monitoring her visually and behaviourally.

Annie was very settled with this regime and as her intracranial pressure increased her medication was altered as required. Annie's family decided that they would like to stay with Annie in the hospice and not return home as they could focus all of their time enjoying being with Annie. The extended family and friends were frequent and regular visitors throughout Annie's stay. Annie died peacefully after two months and the hospice supported the family through the formalities of after death and funeral care. Ongoing bereavement and sibling support will be available for the family.

Whilst Annie did not have a large community nursing or continuing care package many people had been involved in supporting her and her family and with the parents consent they were kept informed of the decisions regarding Annie's management and the progress of her care and visited her and the family in the hospice.

Source: Case study provided by Helen & Douglas House, August 2011

Advanced Care Planning (ACP)

The South Central Strategic Health Authority (2010) identifies that a Child and Young Person's Advance Care Plan (ACP):

1 is designed to communicate the health-care wishes of children who have chronic and life-limiting conditions.	4 is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service.
2 sets out an agreed plan of care to be followed when a child's condition deteriorates.	5 can be used as a resuscitation plan or as an end-of-life care plan.
3 provides a framework for both discussing and documenting the agreed wishes of a child and his or her parents, when the child develops potentially life-threatening complications associated with his or her condition.	6 remains valid when parent(s) or next of kin cannot be contacted.
	7 is usually initiated by a senior clinician who knows the child and his or her family well.

The South Central Strategic Health Authority (2011) suggests the following initiation process.

STEP	ACTION	BY
1	♥ Assessment of the child's clinical situation Has there been a recent change in the prognosis or clinical condition as a result of either a sudden or gradual deterioration?	♥ Any professional involved with the child's care.
2	♥ Discussion with all health care professionals involved with the child whether to prepare to develop an ACP. Consideration as to whether it is appropriate to discuss the DNACPR section of the plan.	♥ Senior clinician.
3	♥ Discussion with parents/legal guardian and child (if appropriate), and other significant family members regarding the need for an ACP.	♥ Senior clinician.
4	♥ When writing the ACP with the parents/guardians allow 1-2 hours, and possibly undertake this in the home setting. The amount of input into this process by the child depends on their capacity for this decision (see section on ethical and legal background).	♥ Senior children's community nurse (CCN)/Palliative care specialist nurse or senior clinician.
5	♥ ACP is completed, dated and signed by parents/ legal guardian, clinician and/or specialist nurse.	♥ Senior specialist nurse and/or senior clinician.
6	♥ Set review date for ACP. The maximum time before review should be no more than 12 months.	♥ Senior clinician.
7	♥ Ensure that all care settings that the child attends have copies of the plan, and receive updated copies as appropriate.	♥ Local ACP co-ordinator.

Full document, policy and guide available at:

→ www.southcentral.nhs.uk/what-we-are-doing/end-of-life-care/childrens-advance-care-plan (accessed 24th July 2011)

My life would be easier if... 'there was someone to look after my mum and dad and brothers and sisters when I die so that they aren't sad.'

Department of Health (2008) *Better Care: Better Lives*

What to do once a child has died?

- 1 If a child's death is expected no immediate action is required although the death should be verified before the body is moved.
- 2 All deaths should be certified using the Medical Certificate of Cause of Death form if a child (aged over 28 days) has been seen by a medical practitioner within 14 days prior to death. Other forms are needed if the child is to be cremated.
- 3 The Child Death Overview panel must be informed of all expected and unexpected deaths.
- 4 Unexpected deaths must be reported to the rapid response team who will activate a review of the unexpected death.
- 5 A coroner may need to be contacted in some circumstances.

Further information can be obtained from:

→ www.direct.gov.uk/en/Governmentcitizensandrights/death/WhatToDoAfterADeath/DG_066713

(accessed 24th July 2011)

The Child Death Review: A Guide for Parents and Carers

This leaflet produced by the Foundation for the Study of Infant Deaths (FSID) gives some useful advice in the event of an unexpected death.

→ www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00180-2010 (accessed 24th July 2011)

or via

→ www.education.gov.uk

Care support and information for a family once their child has died

Care of the child after death may include:

- 1 management by the undertakers.
- 2 body remaining in the family home with additional support e.g. air conditioning units (circumstances may dictate the need for embalming).
- 3 transfer to cool room at a children's hospice.
- 4 bereavement support information, as outlined previously.
- 5 for families who are struggling to pay for funeral, it is possible to apply for funding by completing a form (SF200) available from the funeral director.

RELIGION ISSUES	BUDDHIST	CHRISTIANITY	HINDUISM	JUDAISM	MUSLIM	SIKHISM
Care of the dying/End of life	<ul style="list-style-type: none"> ♥ May not wish sedatives. ♥ Family may wish to wash body. ♥ Provide a place and space of peace and quiet. ♥ Some families may wish for the body not to be touched for as long a possible after the death. (Time for the mind to leave the body) 	<ul style="list-style-type: none"> ♥ Offer a Baptism or blessing for the child if this has not happened. 	<ul style="list-style-type: none"> ♥ Any jewellery and sacred threads should not be removed. ♥ Close eyes and straighten body. May wish to be placed on the floor. ♥ Family may wish to wash the body and wrap it in a white cloth. ♥ Holy water may be applied to the lips. 	<ul style="list-style-type: none"> ♥ May wish to hear Psalm 23 read and the Shema. The body should be handled as little as possible. ♥ After death close eyes, clothing then untouched for a short time (enquire about washing). Family may wish to wash body. Some traditions may wish for same gender contact only. ♥ Most traditions may wish for the child not to be left alone. Separate undertakers. 	<ul style="list-style-type: none"> ♥ May wish for reading before death. ♥ Eyes and mouth closed, body straightened, turn head to the right and cover with clean sheet. ♥ May wish to face Mecca (S.E. direction in UK) Privacy for family to grieve. ♥ Any sacred jewellery should not be removed. Washing has to be in accordance to Islamic faith. ♥ Families may wish to take the child home with them. ♥ Separate undertakers. 	<ul style="list-style-type: none"> ♥ The five K's should not be removed. ♥ Family will read Holy books, there are no priests. ♥ Music or prayers may be played. ♥ Close eyes and straighten body. Family may wish to wash and dress the body. ♥ If the boy is over 5 or puberty, he will wear a turban.
Visit from the religious leader	<ul style="list-style-type: none"> ♥ Call a faith representative to facilitate peace and quiet for meditation. 	<ul style="list-style-type: none"> ♥ Roman Catholic and some CofE require a Priest for last rites, blessing and or Baptism. 	<ul style="list-style-type: none"> ♥ A priest may be required, reading from Holy Books. 	<ul style="list-style-type: none"> ♥ Offer a visit from a Rabbi, but reading are normally lead by the family. 	<ul style="list-style-type: none"> ♥ Offer a visit from an Imam, but prayers are normally lead by the family. 	<ul style="list-style-type: none"> ♥ Offer a visit from a Priest or Chaplain, but reading can be lead by the family.
Organ donation	<ul style="list-style-type: none"> ♥ No religious preference as norm. 	<ul style="list-style-type: none"> ♥ No religious preference as norm. 	<ul style="list-style-type: none"> ♥ No main issues. 	<ul style="list-style-type: none"> ♥ Varied attitudes, referral to rabbi. 	<ul style="list-style-type: none"> ♥ Varied attitudes (allowed majority). 	<ul style="list-style-type: none"> ♥ Varied attitudes, generally ok.
Post mortem	<ul style="list-style-type: none"> ♥ No religious preference as norm. 	<ul style="list-style-type: none"> ♥ No religious preference as norm. 	<ul style="list-style-type: none"> ♥ No religious preference as norm. 	<ul style="list-style-type: none"> ♥ Varied attitudes, some families will be very against it, referral to rabbi. 	<ul style="list-style-type: none"> ♥ Not keen. 	<ul style="list-style-type: none"> ♥ No main issues.
Funeral	<ul style="list-style-type: none"> ♥ Cremation is preferred but will depend on tradition. 	<ul style="list-style-type: none"> ♥ No general preference of burial or cremation. 	<ul style="list-style-type: none"> ♥ Funeral take places ASAP after death. Children may be buried, adults are cremated. Gift of a toy in the coffin for the child to play with while they are in heaven awaiting rebirth. Photo candle/religious symbol at home for 12 days after funeral. 	<ul style="list-style-type: none"> ♥ Funeral take places ASAP after death, 24 hours. A "watcher" sits with the body within some traditions. May prefer burial in separate cemetery. ♥ Mourners do not leave the house. ♥ Mourning for a child is 30 days. 	<ul style="list-style-type: none"> ♥ Funeral take places ASAP after death, 24 hours. Always buried. Funeral prayer will be led by the Imam. Believe in Paradise or Hell (young children assured of Paradise and interceding for parents). 	<ul style="list-style-type: none"> ♥ Always cremated, although babies without teeth maybe buried, mourners sometimes wear white. ♥ Ashes poured into flowing water.
Beliefs about suffering	<ul style="list-style-type: none"> ♥ Suffering is universal and is eased by not being selfish. 	<ul style="list-style-type: none"> ♥ Varied attitudes. Can be fatalistic or angry with God. 	<ul style="list-style-type: none"> ♥ Varied attitudes 	<ul style="list-style-type: none"> ♥ Varied attitudes. 	<ul style="list-style-type: none"> ♥ Death is seen as the will of God. Life span of every individual was allocated at the beginning of time. <i>Subr</i> (patience) is highly encouraged. 	<ul style="list-style-type: none"> ♥ Varied attitudes.
Belief about the after life	<ul style="list-style-type: none"> ♥ Believe in rebirth. 	<ul style="list-style-type: none"> ♥ Believe in life after death in Heaven or Hell. Infants assured of Heaven in most traditions. 	<ul style="list-style-type: none"> ♥ Believe in rebirth. Children enter heaven first. 	<ul style="list-style-type: none"> ♥ Believe in life after death in Heaven or Hell. Infants assured of Heaven in most traditions. 	<ul style="list-style-type: none"> ♥ Believe in life after death in Heaven or Hell. Infants assured of Heaven and pray for family. 	<ul style="list-style-type: none"> ♥ Believe in rebirth.
Gender	<ul style="list-style-type: none"> ♥ Adapt to local culture. 	<ul style="list-style-type: none"> ♥ No main differences. 	<ul style="list-style-type: none"> ♥ Ladies wear Shari at end of life. ♥ Close female relatives only at the crematorium. Gender to gender greeting at home, using holy name of God. 	<ul style="list-style-type: none"> ♥ The Orthodox tradition will prefer same gender care, touch etc. ♥ Some traditions do not have women in mourning prayers (Kaddish). 	<ul style="list-style-type: none"> ♥ Segregation at the funeral. 	<ul style="list-style-type: none"> ♥ Eldest son represents family. Will sit separately at funeral.

Source: West Midlands Children and Young People's Palliative Care Toolkit - Rev Paul Nash Chaplaincy Birmingham Children's Hospital www.act.org.uk/westmidstoolkit then look in the chapter reference Care at Time of Death (accessed 18th August 2011).

Looking after staff working with children who have palliative care needs

A key part of working in children's palliative care is looking after yourself and your colleagues as many situations can be emotionally and physically exhausting. We addressed many ways to gain professional support in the clinical supervision toolkit

which has been developed for professionals who work with children who have palliative care needs in the Thames Valley area available from Helen & Douglas House.

Amongst other issues, the clinical supervision toolkit includes information on:

- setting up clinical supervision.
- debriefing sessions.
- relaxation and mindfulness exercises.
- learning styles.

PA to the Director of Clinical Services
 Helen & Douglas House
 14A Magdalen Road
 Oxford OX3 1RW
 T: 01865 794749
 E: reception@helenanddouglas.org.uk

In their handbook, ACT includes a section on how to survive and thrive in children's palliative care which gives ideas for clinicians to develop resilience in the challenging area of children's palliative care.

As a helpful starter consider the following self help tools:

SELF HELP WEBSITES TO IDENTIFY YOUR STRESSORS	HOW THIS SITE MAY HELP
www.mindtools.com/stress/Brn/BurnoutSelfTest.htm	♥ For a test to see if you are burning out.
www.stress-management-for-peak-performance.com/stress-diary.html	♥ Giving ideas to monitor your stress through a stress diary.
http://c11.psychtests.com/take_test.php?idRegTest=2973	♥ To help you detect if you have depression.
www.goodmedicine.org.uk/stressedtozest/2008/12/handouts-questionnaires-generalized-anxiety-disorder-gad	♥ A range of handouts and tests to help you detect if you have anxiety or are worrying excessively.
http://counsellingresource.com/lib/quizzes/drug-testing/alcohol-cage	♥ To help you detect if you are taking too many harmful substances, such as alcohol.

(accessed on 24th July 2011)

Further reading

Association for Children with Life-threatening or Terminal Conditions (ACT) (2011) *Children's Palliative Care Handbook for GPs*, Bristol: ACT

Buckman, R.A. (2005) *Breaking Bad News: the S.P.I.K.E.S Strategy*, Community Oncology www.communityoncology.net/journal/articles/0202138

Helen & Douglas House (2011) *Clinical Supervision Toolkit: For professionals working with children who have palliative care needs*



References

References

Association for Children with Life-threatening or Terminal Conditions (ACT) and their Families and the Royal College of Paediatrics and Child Health (2003), *A Guide to the Development of Children's Palliative Care Services (2nd Edition)*, Bristol: ACT.

Association for Children with Life-threatening or Terminal Conditions (ACT) (2011), *Children's Palliative Care Handbook for GPs*, Bristol: ACT.

Association for Paediatric Palliative Medicine (APPM) *Formulary for Paediatric Palliative Medicine*
www.act.org.uk/landing.asp?section=385§ionTitle=The+Association+for+Paediatric+Palliative+Medicine+%28APPM%29,
(accessed 4th June 2011).

Craft, A. & Killen, S. (2007), *Palliative Care Services for Children and Young People in England – An Independent Review for the Secretary of State for Health*, London: Department of Health.

Cochrane, H. Liyanage, S. & Nantambi, R. (2007), *Palliative Care Statistics for Children and Young People*, London: Department of Health.

Department of Health (2008), *Better Care: Better Lives. Improving Outcomes and Experiences for Children, Young People and Their Families Living with Life Limiting and Life Threatening Conditions*, London: Department of Health.

Harrop, E. & Parks, H. (2011), *Symptom Management and Palliative Care Guidelines for Paediatric Haematology/Oncology*.

World Health Organisation (WHO) (1996), *World Health Organisation Guidelines: Cancer Pain (2nd Edition)*, Geneva: World Health Organisation.

