

ACT's Best Practice Guide: Prompts for Care in the Last Hours and Days of a Child or Young Person's Life

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Katrina McNamara-Goodger has worked with ACT, the national charity that represents children with life-limiting or life-threatening conditions and their families, since 2004. She worked as a nurse in Merseyside before joining the Department of Health as nursing adviser for

children's services, during which time she led the development, launch and implementation of the Diana, Princess of Wales Community Children's Nursing Teams across England. She is currently the Chair of the UK Council for Children and Young People's Nursing. She has had considerable experience in a health and civil service environment and more recently within the voluntary sector, and is now ACT's Head of Policy and Practice. In 2009, the *Elisabeth Kübler-Ross Award for Outstanding Contribution* was presented to Katrina for her vision in developing the UK's first Integrated Care Pathway for children's palliative care at the Children's Hospice International (CHI) Awards Ceremony.

Summary

The ACT Best Practice Guide, *Prompts for care in the last hours and days of a child or young person's life* aims to provide workers with an easy to reference document that can be easily carried with the worker. While there are many other fuller references to care at end of life, this guide aims to be a short reference document that provides a short list of prompts to support best practice. It was developed with the support of a number of experienced children's palliative care professionals. ACT is the national charity that represents children with life-limiting or life-threatening conditions and their families (www.act.org.uk).

Introduction

This article aims to describe ACT's Best Practice Guide, *Prompts for care in the last hours and days of a child or young person's life*. The guide was produced to support workers as they support children, young people and their families as they care for the child/young person in the last hours and days of that child/young person's life. All four countries in the UK have focused on policy initiatives to support the palliative care of children and young people over the past few years. Drawing on these, the ACT series of documents aims to translate policy into best practice to ensure that children, young people and their families experience high quality of care, wherever they live.

Background

ACT is the only organisation working across the UK to achieve a better quality of life and care for every life-limited or life-threatened child or young person and their family. Our vision for children's palliative care is for well co-ordinated services that enable, support and inform families so that they can exercise real choice relating to:

- choice of place of care
- choice of social opportunities
- choice of place of death
- choice of emotional, psychological and bereavement support.

There are estimated to be 23,500 life-threatened or life-limited children in the UK – and half of these children will have substantial palliative care needs at some point. We use the term 'palliative care' to mean:

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of

short breaks and care through death and bereavement (ACT, 2009).

We use the term 'life-limiting conditions' to mean:

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some conditions cause progressive deterioration, rendering the child or young person increasingly dependent on parents and carers. Life-threatening conditions are those for which curative treatment may be feasible but can fail (ACT, 2009).

The ACT Best Practice Prompts

ACT have developed a series of care pathways that focus on the care provided to children, young people and families as they follow their own unique care journey and the standards of care they can expect at key points along that journey. The pathways focus on the needs of the child and family rather than the service delivering the care.

The ACT Multi-agency Integrated Care Pathway Standard 5 states that:

Every child & family should be helped to decide on an end-of-life plan and should be provided with care & support to achieve this as closely as possible.

It is recognised that it is not always clear or easy to predict the time when a child is likely to move into the final phase of their life. Sometimes, the realisation that death is imminent may be quite sudden, possibly only hours or days before death. For others, the move into the end-of-life phase may be clearer and follow a period of deterioration. For some, it follows decisions to stop all life-prolonging treatment. All professionals working with children and young people, their families and carers should be honest and open about the probability that the child or young person's life is nearing an end.

The ACT Best Practice Prompts are designed to support the worker when it has already been recognised that the child or young person's life is nearing the end. Other ACT documents, such as the series of care pathways, offer fuller information about the discussions about care choices with parents and other family members. The ACT Best Practice Prompts were written to offer workers a simple, easy-to-reference guide for when they are involved in caring for a child or young person at the end of that child or young person's life.

ACT's Best Practice Guide focuses on preparing for an anticipated death in the place of the child and family's choice and on managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately after-

wards. The document aims to ensure that the needs of both child or young person and their family (including siblings) are identified and met throughout the last phase of life and into the post-death bereavement care of the families following their child's death. It includes the management of pain and other symptoms, and provision of psychological, social, spiritual and practical support for the family into bereavement.

We recognise that for families, bereavement does not start with the death of their child. It is typically a series of loss and grief experiences throughout their child's life, starting with the diagnosis of a life-limiting or life-threatening condition. (Some families do not get a true diagnosis for some time but their child is recognised to have a condition which is likely to cause premature death.)

Parental/family information is provided in the *Family Companion to the ACT Care Pathway for children with life-limiting and life-threatening conditions* (ACT, 2009). Parents and other significant family members should be encouraged and supported to continue their caring role with the child or young person at this time.

Prompts for care in the last hours and days of a child or young person's life is a guide to professionals who may not work exclusively in palliative care but who are supporting a family caring for a child or young person at the end of life. The prompts are as follows:

1. The child/young person's needs are assessed and a plan of care is discussed and developed with the child/young person, family and carers, including choice of place of care. Within this assessment, the ability of the child/young person, family and carers to communicate must be considered and appropriate interpreting services ensured.

Ask yourself: *Have I discussed and developed a care plan?*

2. The religious and spiritual needs of the child/young person, family and carers are assessed.

Ask yourself: *Have I asked about spiritual needs?*

3. The insights of the child/young person, family and carers into the child/young person's condition are identified and their wishes and views are incorporated into the care plan.

Ask yourself: *Do I know what everyone understands about the condition?*

4. Emergency contact details for the staff to be contacted are confirmed for the family and carers of the child/young person.

Ask yourself: *Have I documented emergency contact details?*

5. Current medications are assessed and non-essentials discontinued.

Ask yourself: *Has the medication regime been reviewed?*

6. 'As required' subcutaneous and other medication is prescribed according to an agreed protocol to manage symptoms including pain, agitation, nausea and vomiting and respiratory tract secretions.

Ask yourself: *Has the range of potential symptoms been anticipated and prescribed for?*

7. Decisions are taken as to whether to discontinue inappropriate interventions, including blood tests, intravenous fluids and observation of vital signs.

Ask yourself: *Have all invasive and non-essential interventions been reviewed and do I know what these are?*

8. The family and carers are given appropriate written information.

Ask yourself: *Would it help the family to have written information, if so have I provided it?*

9. The GP practice, care team (e.g. CCN services, consultants) and others (e.g. ambulance trust) including out of hours services, are made aware of the child/young person's condition.

Ask yourself: *Have I told all of the professionals who need to know about the current situation?*

10. The family are given an opportunity to discuss their plans for after-death care including who to call, what to do immediately and what can wait.

Ask yourself: *Have the family identified who they would like as support after their child dies?*

Conclusion

Providing care at the end of a child or young person's life is challenging for professionals, as they support the child and family at this highly emotive time. This series of prompts aims to provide support for professionals as they deliver that care by offering a straightforward, jargon-free reference tool that is easy to access.

Sources for further information

ACT www.act.org.uk

Bliss is the special care baby charity which provides vital support and care to premature and sick babies across the UK. www.bliss.org.uk

Child Bereavement Charity offers specialised training and support for professionals whose work brings them into contact with bereaved families.

www.childbereavement.org.uk

Winston's Wish is a leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families.

www.winstonswish.org.uk

ACT (2009) *A Guide to the Development of Children's Palliative Care Services*, 3rd Edition

ACT (2004) *Framework for the Development of an*

Integrated Multi-agency Care Pathway for Children with Life-limiting Conditions, London

ACT (2007) *The ACT Transition Care Pathway: A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions*

ACT (2009) *A Family Companion to the ACT Care Pathway for children with life limiting and life threatening conditions*

ACT (2009) *A Neonatal Pathway for Babies with Palliative Care Needs*