Using a Care Pathway Approach

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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.

- Campaign for the development of children's palliative care services.
- Work with professionals to develop best practice
- Empower and support families

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ACT works across the UK and has three strategic aims:

1. Lobbying for sustainable children’s palliative care services & raising awareness
2. Working with professionals to develop best practice and build the research evidence base
3. Empowering and supporting families with information
What I will be covering:

- What is a care pathway?
- Why the ACT care pathway was developed
- How a pathway approach can help
- Key issues; standards and goals along the way
- Resources to support you
What is 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, 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/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
A CYP Palliative Care Journey

• From Diagnosis through Living with the Condition to End of Life Care, Death and beyond (ACT)
• Each care journey is unique – as each life is unique.
What is a Care Pathway?

• The concept of integrated care pathways can be traced back to the 1980s when clinicians in the USA began to develop “Anticipated Recovery Pathways” to define delivery of care that focused on the patient rather than the system.

• ACT developed the first integrated care pathway for children and young people with life-threatening/life-limiting conditions and their families in 2004, followed by the publication of a transition care pathway in 2007 and a neonatal pathway in 2009
What is a Care Pathway (cont)?

- The pathway is guided by essential (sentinel) standards, based where possible, on evidence.
- The focus is on the child/family rather than the system
- Children and their families make many different individual journeys according to their own needs and circumstances
- For the ACT Pathways, the Stages are:
  - entry to the pathway,
  - moving through the pathway and
  - leaving the pathway
ACT Multi-agency Integrated Care Pathways provides a guide to:

**What** we should do

Also need to establish:

**How** we can apply it to our individual areas and for individual families

Taking into account:

- differing & variable resources
- differing & mixed geography

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How the pathway developed

• Aims to fill a gap (policy to practice)
• Involved parents & young people & other “grassroots” experts from the outset
• Part of the ACT Care Pathway series – style agreed – definition agreed
• Focus groups/use of email discussions
• Off the shelf version for personalisation:
• This is the start of the work not the end!
What do Children/Young People and their families want?

They have told ACT they want:

- Choices/options in all aspects of care, including therapies and death in the place of choice;
- Coordination of services at home, where this is the chosen place of care, including provision of specialist equipment and access to 24-hour specialist advice and expertise;
continued

- Expert symptom management;
- Emotional, spiritual and practical support for all family members;
- Short breaks, with medical and nursing input, when required
- To be seen as a person 1st, their condition 2nd
continued

More Than My Illness, CLIC Sargent (2009) identifies
• Being Able to Go Home
• Keeping up with education
• Keeping up with social activities
• Transition and Home Visit Support
• Emotional Support
• Finance and Employment
• Practical Support
• Information
• Support for the Whole Family
• Individual, Needs-led Support
Aims of the pathway

- This document aims to facilitate the development of care pathways for children with all types of life-limiting and life-threatening conditions in all settings
- Aims to link service users and service providers through one planning process
- Promote equity of care
How?

Provides standards
Suggests goals
Service self assessment tools [www.act.org.uk](http://www.act.org.uk)
Family assessment tool
Ongoing development of other pathways:

[ACT for children](#) [ACT for families](#) [ACT together](#) [ACT now!](#) [www.act.org.uk](http://www.act.org.uk)
The phases & sentinel standards

• Breaking News
  1: Sharing significant news
  2: Preparing for going home

• Living with the condition
  3: Multi-agency assessment of family’s needs
  4: Multi-agency care plan

• End of life
  5: End of life care
1. Every family should receive the disclosure of their child’s prognosis in a face-to-face discussion in privacy & should be treated with respect, honesty & sensitivity. Information should be provided both for the child & family in language that they can understand.

2. Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving the hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

3. Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.

4. Every child and family should have a multi-agency care plan agreed with them for the delivery of coordinated care and support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.

5. 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.

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Breaking news

Every family should receive the disclosure of their child’s prognosis in a face-to-face discussion in privacy & should be treated with respect, honesty & sensitivity. Information should be provided both for the child & family in language that they can understand.
Key goals in breaking bad news

- Good practice in breaking bad news has been described by SCOPE
- Plenty of time
- Place for privacy
- Parents should be together to hear news
- Helpful written material
- Information conveyed in readily understandable language

ACT Charter also states
- Parents should be treated with openness and honesty
- Parents should be acknowledged as experts in the care of their children
- The needs of the child for info appropriate to their age & understanding should also be taken into account
Planning for going home

Every child & family diagnosed in the hospital setting, should have an agreed transfer plan involving the hospital, community services & the family, & should be provided with the resources they require before leaving hospital.
Key goals in planning transfer to home and community

• Planning should begin asap & a clear plan for transfer should be agreed with child, family, hospital & community services
• Community services should be notified as soon as practical
• There should be community in-reach to the family in hospital, in person wherever possible or via telephone
• A lead CCN should be agreed before transfer, the child’s GP should be invited to become involved & clear plans should be in place for shared medical care
• Equipment & supplies should be provided before transfer
• Training should be provided for carers before transfer
• Clear lines of communication should be agreed
• A home visit should be arranged within 3 days of transfer
• 24hr contact number should be provided to the family
• Where possible a key worker should be identified
Multi-agency assessment of Family’s needs

Every family should receive a multi-agency assessment of their needs ASAP after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.
Key goals in assessment

• Children & families should have their needs assessed asap after diagnosis or recognition
• A holistic & multi-agency approach should be used to avoid the need for multiple assessments
• Assessment of needs should be in partnership with the family
• The C or YP should be kept in focus & involved in the process
• Care should be taken to include the needs of fathers & siblings
• Individuality and ethnicity should be respected
• Info should be gathered and recorded systematically to ensure consistency
• Straightforward, non-jargon language should be used
• The issues of confidentiality & consent should be addressed
• Assessment information gathered should be available to the family
• There should be clarity in respect of the lead role
• Those undertaking needs assessments should have appropriate skills and local knowledge

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Multi-agency care plan

Every child & family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care & support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.
Key goals for the Multi-Agency Care Plan

• Every family should have a key worker to co-ordinate the plan
• Info should be available for the child & family
• The plan should include the whole family and take account of:
  • Child’s symptoms & personal care
  • Psychological care for C & F
  • Access to benefits & financial assistance
  • Access to flexible short breaks
  • Access to education
  • Protection of carers’ health
  • Access to aids & equipment
  • Transition to adult services

Key goals in reviewing needs

• The C & F needs should be regularly reviewed
• The family should be able to request a review at any time
• Services & Professionals should regularly review their effectiveness in co-ordinating & delivering care plans
• Families will need extra support at key times, particularly following hospital admission, a change in the child’s condition or in times of family crisis
• A change in prognosis should be communicated to the family
• A new care plan should be agreed to take account of changes
End of life plan

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.
Key goals in planning for EOL care

• Professionals should be open & honest with families when the approach to EOL care is recognised
• Joint planning with families & relevant professionals should take place asap
• A written plan of care should be agreed including decisions about methods of resuscitation; emergency services should be informed
• Care plans should be reviewed and altered to take account of changes
• There should be 24hrs access to pain & symptom control including access to medication
• Those managing the control of symptoms should be suitably qualified and experienced
• Emotional & spiritual support should be available to the child and carers
• Children & families should be supported in their choices & goals for quality of life to the end

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ACT Resources

- Care Pathways (transition/neonatal/children)
- Audit tools
- Definitions and Descriptions papers
- Transition coordinators/ partnership
- Networks/ E-community
- Right People, Right Place, Right Time
- National Mapping Initiative/Minimum Dataset
- A Family Companion to the ACT Care Pathway for children with life limiting and life threatening conditions (2009)
ACT Resources

• Voices for Change London (ACT 2003)
• Quality Markers in CPC (ACT 2009)
• Symptom control manual
• Competences
Other Resources

- Bliss is the special care baby charity [www.bliss.org.uk](http://www.bliss.org.uk)
- Well Child [www.wellchild.org.uk](http://www.wellchild.org.uk)
- ICPCN [www.icpcn.org.uk](http://www.icpcn.org.uk)
- Family Fund [www.familyfund.org.uk](http://www.familyfund.org.uk)
- Young Carers [www.youngcarers.net/](http://www.youngcarers.net/)
- Sibs [www.sibs.org.uk](http://www.sibs.org.uk)
- Goldman, Hain & Liben (Eds.). *Oxford Textbook of Palliative Care for Children* 2006 Oxford University Press
Thank you!

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