Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions

ACT’s care pathway approach
ACT is the UK charity working to achieve the best possible quality of life and care for every child who has a life-limiting or life-threatening condition and their family. ACT advocates a care pathway approach to delivering care and support to children and families throughout their journey; from diagnosis to end of life and into bereavement. Pathways can 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, in the right place and at the right time. ACT has developed a range of care pathways for babies, children and young people that provide a generic framework which service providers or commissioners can adapt locally.

ACT has also developed a dedicated family companion to its care pathway, as well as a series of assessment tools to measure the success of your pathway approach.

This document has been designed to introduce you to ACT’s Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions, to share how it is structured and to give you overview diagrams of the three stages of the pathway.
ACT’s first care pathway was developed as a tool to help professionals in planning appropriate care for children with life-limiting and life-threatening conditions and their families, and in co-ordinating the various services and individuals that will play a part in a child’s care. It concentrates on the needs of children and their families at key points along their care journey and places the child and their family at the centre of the planning process.

The pathway aims to facilitate the development of local integrated care pathways for children with palliative care needs, irrespective of the setting of care and to link children and their families with community services, hospital based services, social care, education and the voluntary sector in one joined-up process.

It has three stages, each relating to a particular stage in the child’s life. Diagnosis or recognition of a life-limiting condition represents entry to the pathway or the first stage; living with a life-limiting condition, or the “maintenance stage”, is described in the second stage; and thirdly end of life and bereavement is the final stage. The template sets down five standards along the pathway:

**Stage One:**
Diagnosis or recognition of a life-limiting condition
- First standard: Breaking news
- Second standard: Planning for going home

**Stage Two:**
Living with a life-threatening or life-limiting condition
- Third standard: A multi-agency assessment of the family’s needs
- Fourth standard: A multi-agency care plan

**Stage Three:**
Recognition of end of life and bereavement
- Fifth standard: An end of life plan

**Help in developing a local or regional care pathway approach**
ACT is committed to supporting individuals and organisations to develop care pathways for babies, children and young people with palliative care needs. If you would like to discuss ACT’s care pathway approach or would like any support or guidance in developing a pathway for your service, please contact ACT. ACT can also provide you with self-assessment tools so you can measure the success of your pathway.

You can read more about ACT’s care pathways for babies, children and young people at: [www.act.org.uk/carepathways](http://www.act.org.uk/carepathways)
Diagram 1: Diagnosis or recognition of a life-limiting condition

Identification of concern (Referral to paediatrician)

Clinical assessment of the child

Diagnosis or recognition of life-threatening or life-limiting condition

Prognosis

Breaking news

The First Standard

Deterioration of long-term condition

Planning for going home

The Second Standard

Immediate needs:
- Information
- Training
- Transport
- Support groups
- Emotional support for parents/siblings/friends

Early liaison meeting

Immediate needs:
- Symptom control
- Medication
- Equipment
- Information
- Follow-up

Early liaison with:
- Family
- GP and Primary Care Team
- Hospital team
- Multi-disciplinary community team
- Social services

Family/carers

Child/young person

Family home

Full multi-agency assessment

Parental/GP concern
- Pregnancy scan
- Critical event (illness/injury)

Place/people
- Information
- Emotional support
- Interpreter

Child health screening
- Newborn examination
Diagram 2: Living with a life-threatening or life-limiting condition

Multi-agency assessment of child’s and family’s needs

Family/carers
- Information needs
- Financial review
- Emotional needs
- Sibling well-being
- Family functioning
- Respite/short breaks
- Quality of life
- Interpreter
- Transition to adult services
- Genetic counselling

Child/young person
- Symptoms/pain
- Personal care needs
- Therapies
- Emotional support
- Information
- Short breaks
- School/leisure
- Quality of life
- Young person’s transition plan
- Independent living needs

Environment
- Home assessment
- Equipment needs
- Transport needs
- School
- University/college

The Third Standard

Clinical lead
- Family GP

Multi-agency care plan
Interventions

Family/carers
- Psychological support
- Training
- Access to benefits
- Parent support group
- Sibling group
- Respite/short breaks
- Pharmacy/supplies

Child/young person
- Symptom management
- Personal care
- Nursing support
- Educational support
- Social and leisure activities
- Short breaks
- Psychological support
- Independent living advice

Environment
- Home adaptations
- Aids/equipment
- Motability

The Fourth Standard

Review of needs

Acute or planned admission

Discharge back to Community team

Review of prognosis

Recognition of end of life
Diagram 3: End of life and bereavement

**Recognition of end of life**

**Assessment of end of life needs and wishes**

**End of life plan**

- **Family/carers**
  - Practical support
  - Sibling involvement
  - Emotional support
  - Spiritual issues
  - Cultural/religious issues
  - Funeral planning
  - Organ donation
  - Grandparents

- **Child/young person**
  - Pain/symptom control
  - Quality of life
  - Friends
  - Emotional support
  - Spiritual issues
  - Cultural/religious issues
  - Funeral planning
  - Organ donation
  - Resuscitation plan
  - Special wishes/visits
  - Memory box

- **Environment**
  - Place of death
  - Ambience
  - Place after death

**Death**

- **Family/carers**
  - Family support
  - Practical help
  - Sibling care
  - Contacts
  - Bereavement support

- **Child/young person**
  - Funeral
  - Burial/cremation

- **Environment**
  - Place to be with the body
  - Ambience

**Post death**

- **The Fifth Standard**
- **Organ Donation**
How to order your ACT care pathway

You can buy a copy of ACT’s Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions at ACT’s online shop or call ACT on 0117 916 6422 or email info@act.org.uk

Online Shop: www.act.org.uk/shop

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ACT’s care pathway series also includes:
The Transition Care Pathway
A Neonatal Pathway for Babies with Palliative Care Needs
A Family Companion to the ACT Care Pathway

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If you need any help developing a care pathway please contact ACT at info@act.org.uk or visit: www.act.org.uk/carepathways

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ACT is the only organisation working across the UK to achieve the best possible quality of life and care for every child and young person who has a life-limiting or life-threatening condition and their family.

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