

Introducing the ACT Care Pathway Series

A Neonatal Pathway for Babies with Palliative Care Needs



Valuing short lives

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. 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 A Neonatal Pathway for Babies with Palliative Care Needs, to share how it is structured and to give you overview diagrams of the three stages of the pathway.

A neonatal pathway for babies with palliative care needs

Ninety eight per cent of neonatal deaths occur in the clinical environment of a hospital setting. Some of these babies, especially those for whom there is no hope of cure, could be transferred to their family's home or a local children's hospice, with appropriate support.

A Neonatal Pathway for Babies with Palliative Care Needs has been developed primarily to help support those professionals working in maternity, obstetric and neonatal units who care for babies in the first 28 days of life who have a life-threatening or life-limiting condition. It aims to encourage practitioners to ensure that the appropriate care is available in the right place, at the right time for each of these babies. It draws together the professionals and resources needed to accompany the baby and family along their unique care journey.

The pathway is designed to be started either antenatally or prior to discharge from hospital and follow the baby through to the community as soon as the baby's condition is recognised as life-limiting or life-threatening.

This pathway has three key stages, is guided by six sentinel standards and provides a template to ensure that the baby and family are always at the centre of the care planning process:



Stage One: Entry to the pathway

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: End of life and bereavement

Fifth standard: An end of life plan **Sixth standard:** Continuing bereavement support

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

Diagram 1: Stage One: Entry to the pathway

Critical event Antenatal screening **Identification** Parental/professional Newborn examination concern of concern Antenatal scan/tests Clinical assessment of the baby **Diagnosis or recognition** Advocacy of life-threatening/life-limiting condition/prognosis **The First Standard Breaking news Family Baby Environment** Information – choices Symptom control Place of care Training in care of baby Emergency care plan People involved in future care **Transport** Baby care needs GP and primary health team **Siblings** Religious and spiritual care Midwifery team Contact details for professionals Hospital team: neonatal and paediatric services Post-natal care of mother Social services Bereavement support Registration of birth Interpreters **Emotional support** Religious and spiritual support **The Second Standard** Planning for going home **Baby Family Environment** Information – choices Place of care Symptom control Training in care of baby Equipment GP and primary health team **Transport** Follow-up (routine/emergency) Midwifery team Siblings Religious and spiritual care Hospital team: neonatal and paediatric services Contact details for professionals Baby care needs Social services Post-natal care of mother Bereavement support Interpreters

Discharge/transfer to family home/less technological care

Stage Two: A multi-agency assessment of the family's needs

A multi-agency assessment of the family's needs

The Third Standard

Family

Information – care choices
Support in care of baby
Sibling well-being
Contact details for
professionals
Post-natal care of mother
Financial/benefits advice
Emotional needs
Family functioning
Respite/short breaks

Interpreter
Genetic counselling

Baby

Symptom control
Equipment
Follow-up (routine/emergency)
Baby care needs
Therapies

Environment

Family
GP and primary health team
Midwifery team
Hospital team: neonatal and
paediatric services
Social services

A multi-agency care plan

The Fourth Standard

Family

Psychological support
Training
Access to benefits
Parent support group
Sibling support
Respite/short breaks
Pharmacy/equipment supplies

Baby

Symptom management
Baby care needs
Nursing support
Therapies

Environment

Potential home adaptations
Aids/equipment
Motability/Blue Badge Scheme

Recognition of end of life

Stage Three: End of life and bereavement

Post-natal care of mother

Memory box

An end of life plan **The Fifth Standard Baby Family Environment** Information – choices Symptom control Place of death **Transport** Equipment Place after death Follow-up (routine/emergency) Sibling involvement **Ambience** Contact details for Spiritual issues professionals Cultural/religious issues **Emotional support** Allowing a natural Spiritual issues death care plan Cultural/religious issues Funeral planning Heart valve donation Grandparents

Continuing bereavement The Sixth Standard support **Baby Family Environment** Information – choices **Funeral** Place of care Transport **Burial/cremation** Ceremony/ies following the death of baby Sibling involvement Registration of death Contact details for professionals **Ambience Emotional support** Spiritual issues Cultural/religious issues Funeral planning **Grandparents** Post-natal care of mother

How to order your ACT care pathway

You can buy a copy of A Neonatal Pathway for Babies with Palliative Care Needs 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

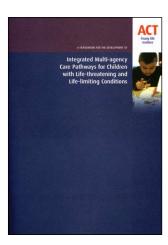
A Neonatal Pathway for Babies with Palliative Care Needs Published November 2009 ISBN No: 1 898447 13 6

ACT's care pathway series also includes:

Integrated Multi-agency Care Pathways for Children with Life-threatening or Life-limiting Conditions The Transition Care Pathway

A Family Companion to the ACT Care Pathway







You can see ACT's full range of publications and resources at our online shop: www.act.org.uk/shop

ACT members are entitled to 25% discount on all ACT publications. To find out how you can become a member visit: www.act.org.uk/join or call ACT on 0117 916 6422

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



Valuing short lives

ACT Brunswick Court, Brunswick Square, Bristol, BS2 8PE

T: 0117 916 6422 F: 0117 916 6430 E: info@act.org.uk

www.act.org.uk

Helpline: 0845 108 2201

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.

ACT is a registered charity and a company limited by guarantee. Registered Charity No. 1075541 Company Registration No. 3734710 England