

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

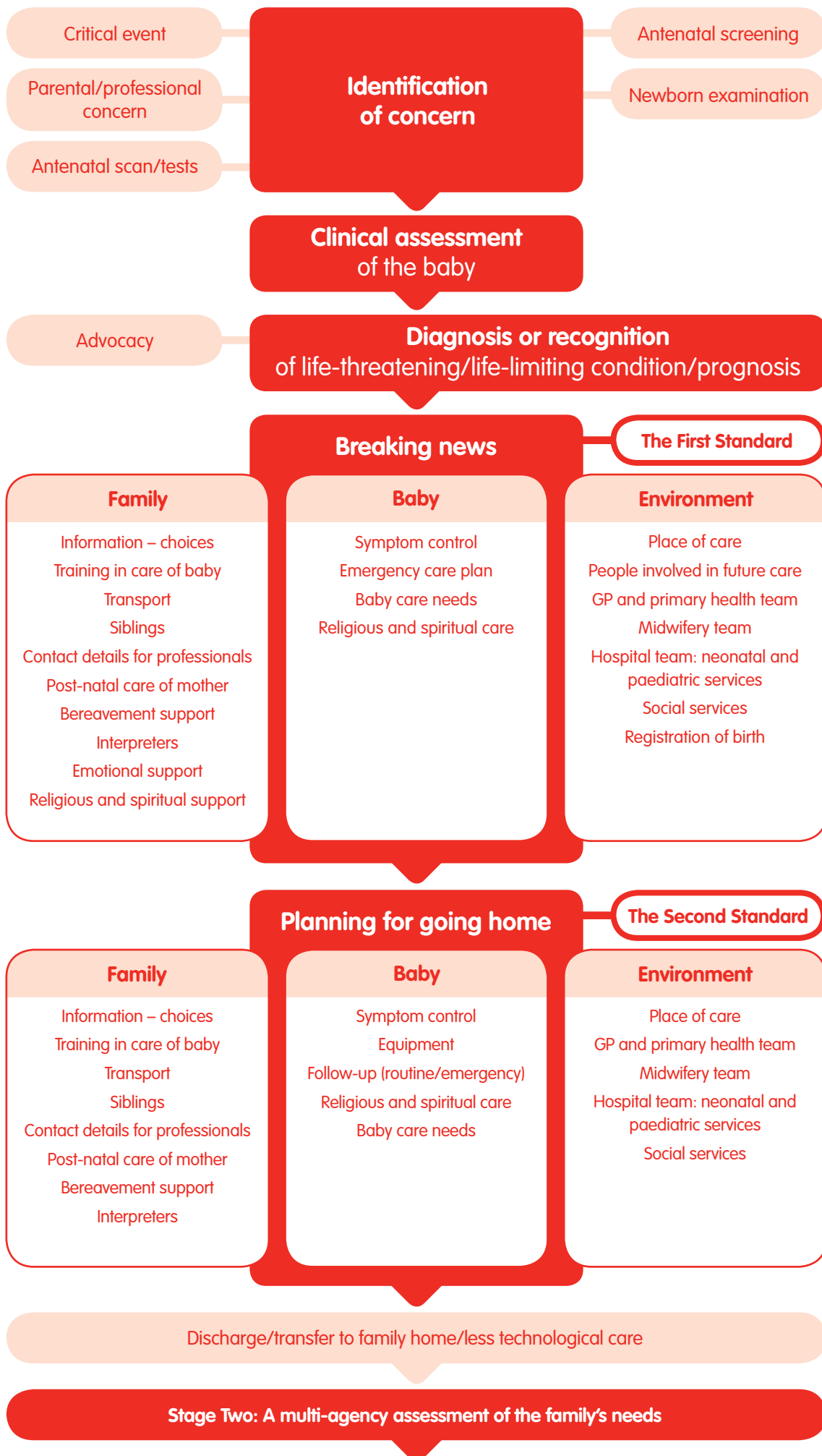


Diagram 2: Stage Two: Living with a life-threatening or life-limiting condition

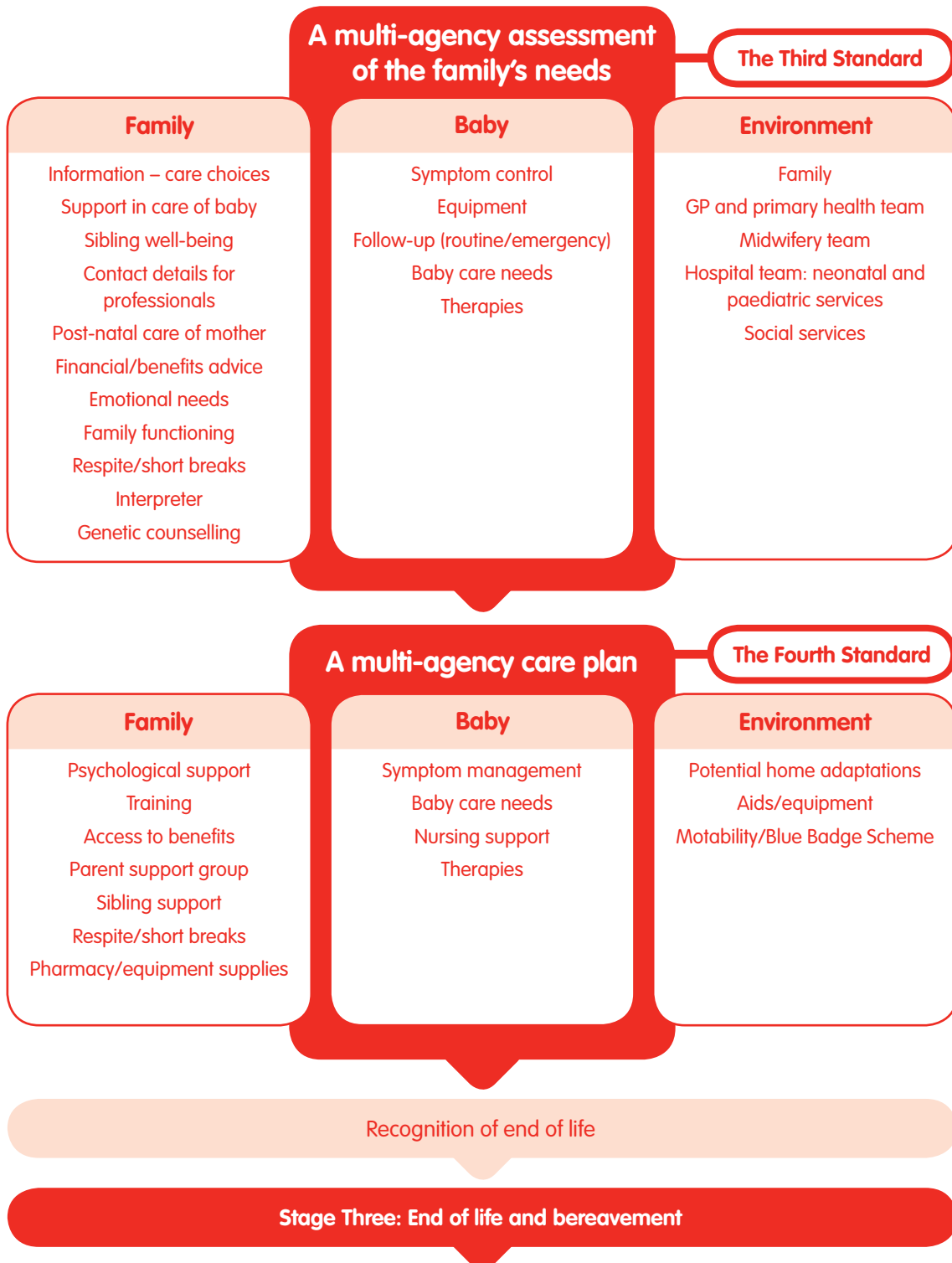
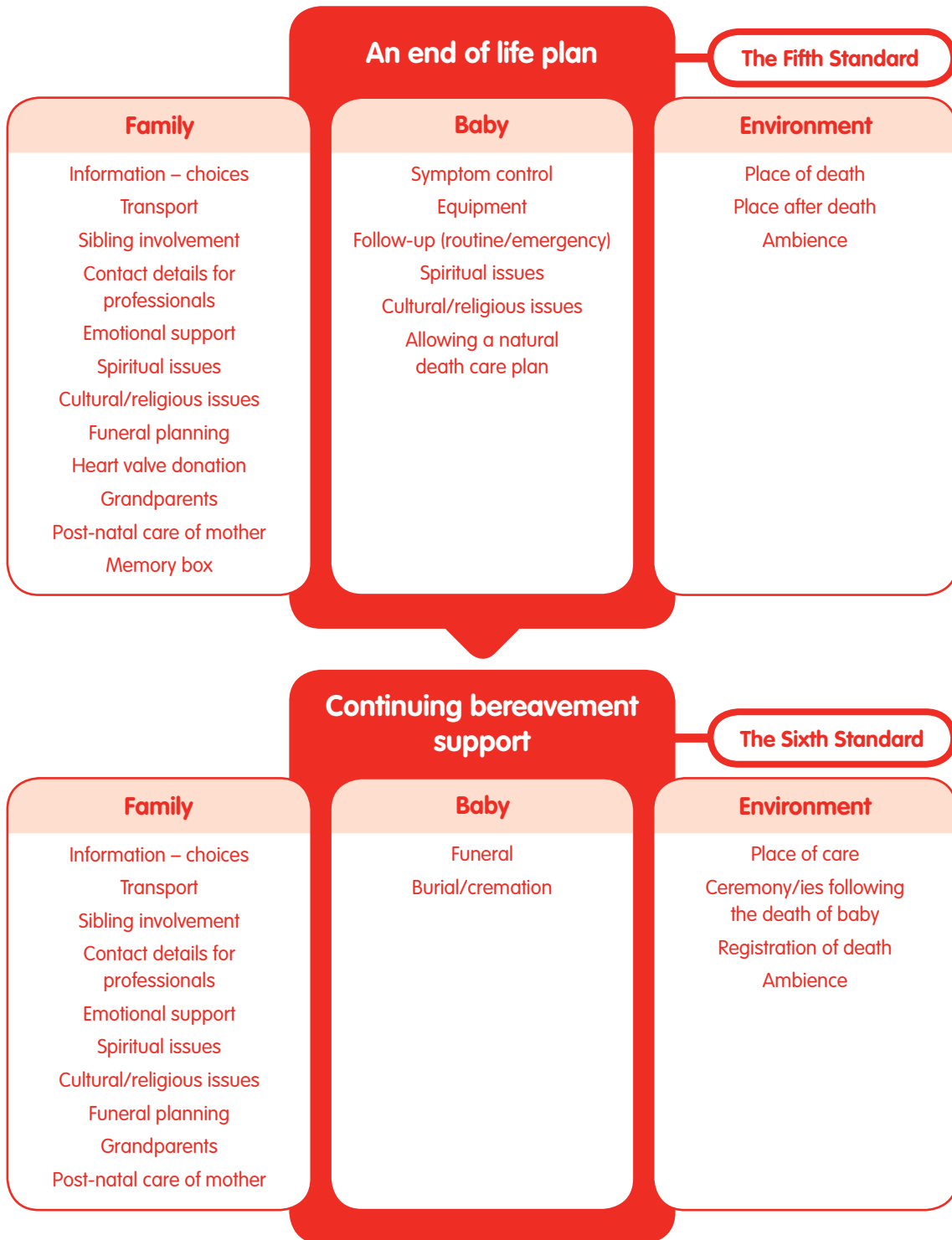


Diagram 3: Stage Three: End of life and bereavement



How to order your ACT care pathway

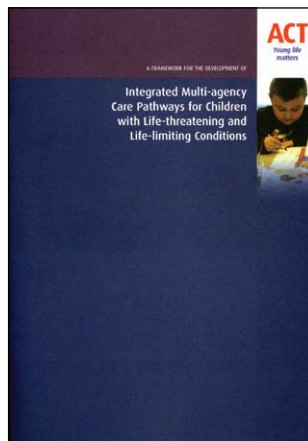
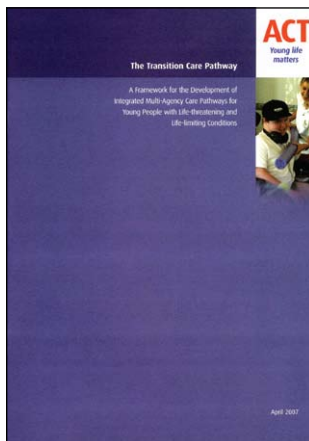
You can buy a copy of *A Neonatal Pathway for Babies with Palliative Care Needs* at ACT's online shop or call ACT on 0117 916 6422 or email info@act.org.uk

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

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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



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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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