

Antenatal and Neonatal Services

Information for Professionals



Antenatal and Neonatal Services

For most families, being pregnant is an exciting time and the birth of a child will be a happy, uncomplicated event. Sadly, some babies are diagnosed in utero or born with a life-limiting condition. Martin House provides support for these families, offering one to one, family-led care at home, in hospital and at our hospice.

This booklet provides information for professionals considering palliative care options and explains how to refer families to Martin House for support.

“Children’s palliative care 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 symptoms, provision of short breaks and care through death and bereavement.”

Together for Short Lives



Our team can support neonatal professionals to explore options when balancing curative care with palliative care. Not all babies will have a diagnosis but if the prognosis of a life-limiting condition is made, either in utero or after birth, professionals can make a referral for support. We also offer parallel planning for babies where it is difficult to predict the prognosis.

The British Association of Perinatal Medicine (BAPN) has identified five categories of perinatal palliative care referral criteria for babies. These are:

Category 1

An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival e.g. anencephaly or bilateral renal agenesis.

Category 2

An antenatal or postnatal diagnosis of a condition that carries a high risk of significant morbidity or death e.g. severe bilateral hydronephrosis and impaired renal function.

Category 3

Babies born at the margins of viability, where intensive care has been deemed inappropriate.

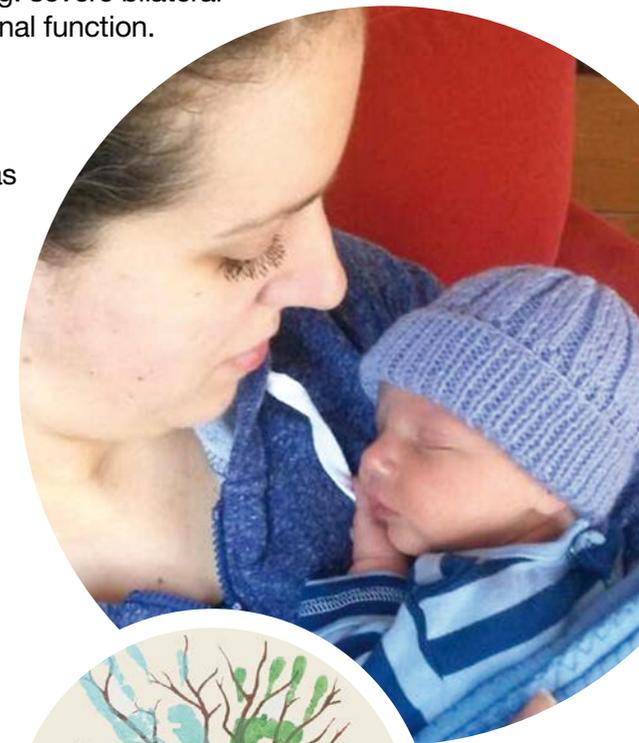
Category 4

Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support e.g. severe ischemic encephalopathy.

Category 5

Postnatal conditions which result in the baby experiencing “unbearable suffering in the course of their illness or treatment” e.g. severe necrotising enterocolitis, where palliative care is in the baby’s best interests.

(BAPN 2016)



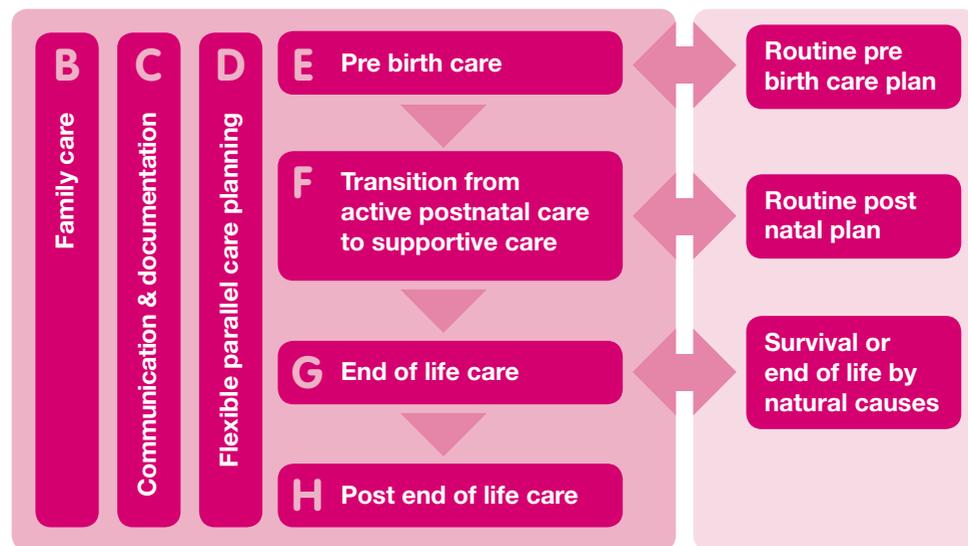
Palliative Care Planning

Palliative care planning should begin once the family opt to follow a palliative care pathway. This should involve a multidisciplinary team including the family, obstetricians, midwives, neonatal staff, community staff, and children's hospice services.

There should be flexibility to meet the individual needs of the baby and family, with all viable options for treatment and place of care considered. This enables the family to make an informed choice and ensures a smooth transition to palliative care services.

Stages of Palliative Care Planning

A Establish eligibility of fetus or baby for palliative care



The British Association of Perinatal Medicine. Palliative Care (supportive and end of life care): A Framework for Clinical Practice in Perinatal Medicine (2010)

Following the delivery of bad news, whether antenatal or postnatal, there are pathways of care that professionals can follow. Sometimes these will need to be implemented quickly. At other times it can be a more gradual process. You can find more information and guidance on our website at www.martinhouse.org.uk.

How can Martin House help?

Martin House offers palliative care services for babies and their families from across West, North and East Yorkshire. We support families in hospital, at home, or at our hospice, according to the needs and wishes of the family.

If a baby is no longer responding to active treatment, we can arrange reorientation of care at home or at the hospice.

We are experienced in meeting complex needs, including:

- compassionate extubation
- discontinuing life-sustaining infusions, such as Prostin
- multi-organ failures
- necrotising enterocolitis
- hypoxic-ischemic encephalopathy

Regardless of the baby's underlying condition, our emphasis is always on ensuring effective symptom management and enabling the family to spend quality time with their baby.

Our team includes palliative care consultant paediatricians; specialty doctors; a specialist registrar in paediatric palliative medicine; paediatric, general and learning disability nurses; allied health professionals; social workers; and a consultant clinical psychologist.



At the hospice

Our hospice offers a home from home setting allowing families as much privacy or support as they need. Our skilled palliative care team is experienced in delivering one to one, family-led palliative and end of life care to babies with a variety of complex needs.

We work in partnership with local community midwives to enable families to make the transition to the hospice immediately after discharge from hospital, and offer mums appropriate postnatal care during their stay.

We have been supporting families for over 30 years and know that they value the support offered during their stay, such as:

- being able to sleep in the same room as their baby, knowing that medical and nursing support is available 24 hours a day
- fulfilling their hopes of normality, such as being able to take their baby into our gardens and spending time as a family
- balancing their expectations of parenthood and independence with the specialist palliative care offered by our team
- having household tasks such as meals and laundry taken care of so that they can spend time with their baby



Symptom control

Babies' symptoms are often unpredictable, but our skilled palliative care team are able to offer high levels of symptom management, including alleviating troublesome symptoms such as continual seizures, pain and agitation.

We offer advanced care planning and Limitation of Treatment Agreements (LOTA) in conjunction with the family to ensure care delivery is as smooth and coordinated as possible, working with other services where appropriate.

Support at home

Not all babies discharged from the neonatal unit are expected to die imminently. We offer ongoing support at home as a step down from hospital, write care plans and LOTAs with the family's consent, and help families to prepare for time at home with their baby.

Our community palliative nursing team offers respite care at home as well as arranging local services to provide ongoing support. We can provide home visits to ensure that symptoms are well managed and to offer advice on symptom management. Our doctors can also offer home visits when appropriate.

End of life care and bereavement support

We provide care for babies in the end stages of their illness, and support their families. Following death, we have cooled bedrooms and a cooled "cuddle cot" that enable a baby to be cared for at the hospice or at home. We offer support to families during this time, from helping with funeral planning to registering the birth and death of their child, something that we can facilitate at home or at the hospice.

Bereavement support is offered to all families whose child had a life limiting condition and includes both individual support for parents and groups for parents, grandparents and siblings. We have a well-established bereavement team and specialist bereavement counsellors to provide support following the death of a child. Families can also access support whether or not they choose to access hospice care from Martin House.

Therapeutic support

At the hospice, we are able to provide music and art therapy as needed. We also have beautiful gardens with a large play area for siblings, and offer complementary therapies, a hot tub, sensory room and a large play room.

Families can choose to care independently for their child with support as needed, or allow our team to lead on care whilst they enjoy cuddles and making memories. At the hospice, we can support families with anticipatory grief, end of life care planning, and the period immediately following their baby's death.



How to Contact Us

We are available 24 hours a day for urgent referrals and professional advice.

Call us on:

01937 845045 (Switchboard) Monday – Friday 9am – 5pm

01937 844836 (Care Team) 24 hours

Email us at:

care@martinhouse.org.uk

You can find a routine referral form on our website (below). We recommend that urgent referrals be made over the telephone.

Visit our website at:

www.martinhouse.org.uk

If you require any further information, please do not hesitate to contact us.



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