Caring for your baby when the future is uncertain

An information booklet for parents about perinatal palliative care

Bliss
for babies born premature or sick

together for short lives

Contents

For information and support about children's palliative care, you can contact the Together for Short Lives Family Support Hub:

Helpline – 0808 8088 100
helpline@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk/get-support

For information and support about looking after your baby on a neonatal unit and at home, you can contact the Bliss support team:

hello@bliss.org.uk
www.bliss.org.uk/parents/support

Published June 2024

Introduction

This booklet is a resource for parents who have had conversations with their care team, either during pregnancy or after birth, that their baby's future is uncertain.

It aims to provide you with information and sources of support when there is uncertainty about your baby's future and they may need palliative care.

We hope that it will help guide you through this time and help you think about the best care for your baby and the support you need as a family.

This resource has been written together by Together for Short Lives and Bliss.

We hope that it will…

1. Support you in caring for your baby
2. Provide you with information on planning for your baby's care
3. Help you to understand what palliative care is
4. Help you to understand what hospice care is
5. Signpost you to sources of information and support

All web links to supportive resources and organisations are at the end of this booklet.

Words and phrases you might hear

Here are definitions of some of the words and phrases that we have used in this booklet and that you might hear in specialist antenatal clinics and/or neonatal units which may also be referred to as neonatal intensive care unit (NICU) and/or the special care baby unit (SCBU).

Palliative care is an active and total approach to care, from the point of diagnosis or recognition that the future is uncertain, through to the baby's or child's death and the family's bereavement. It includes physical, emotional, social and spiritual elements of care, focusing on enhancing quality of life and comfort for the baby or child and support for the family.

Children's hospice services provide care for babies, children and young people with life-limiting conditions and their families. Children's hospice services can deliver this care in a purpose built building and/or in the home (commonly termed 'hospice at home').

End of life care is provided when it is recognised that the baby or child's death is likely to happen soon. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death and immediately afterwards. It enables the support and palliative care needs of both the baby or child, and their family, to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms, as well as provision of psychological, social, spiritual and practical support for the family into bereavement.

Life-limiting condition is a condition (sometimes called a life-shortening condition) for which there is no reasonable hope of cure and from which a baby or child will likely die.

Life-threatening condition is a condition for which curative treatment may be possible but can fail, such as children with cancer.

Supportive care is an 'umbrella' term for all services which may be required to improve the quality of life for people with life-limiting or life-threatening conditions.

Diagnosis means identifying an illness or other condition by looking at the symptoms.

Prognosis is the likely course of a condition or illness and can include anticipated life expectancy.

You can visit Bliss' website for a full list of words and phrases you may hear on the neonatal unit.

All useful links can be found at the end of this booklet.

Caring for your baby on the Neonatal Unit

Whilst on the unit, you should be supported to become an expert in caring for your baby. If your baby was born seriously unwell, it is likely that you were separated from them soon after they were born. Arriving on a neonatal unit and watching the staff care for your baby can make many parents feel like they aren't able to care for their baby as they would like.

Here are some things you can talk to your care team about to help you be close to your baby and involved in their care while on the unit:

Skin-to-skin

Sometimes called 'kangaroo care', this means placing your baby undressed onto your bare skin on your chest, so that your skin touches. This is shown to help you to connect with your baby, as well as calming them if they are feeling pain or stress. Mums, dads, brothers, sisters and other family members can do skin-to-skin. Staff will let you know if your baby is ready to have skin-to-skin with you – sometimes you might need to wait until they are more stable.

Feeding

Most babies on the neonatal unit can have breast milk, donor breast milk, or formula milk. Your baby may not be able to be breastfed straightaway or may have expressed breast milk through a tube. Whether you are tube feeding, breastfeeding or bottle feeding your baby, you can get involved. Many parents tell us that having skin-to-skin whilst feeding, expressing breast milk or giving their baby their first bottle feed gives them lasting memories that they treasure.

Washing and changing

The nurses and neonatal team can support you to wash your baby and change their nappy. This can feel hard when they are connected to wires and monitors. The nurses will show you the best way to do this to make sure your baby feels comfortable. Doing these things, sometimes called 'your baby's cares', can help parents feel connected with their baby.

Getting to know your baby

Sometimes it might feel like you spend a lot of time just looking at your baby. This is really important. It can help you to learn how your baby shows signs of pain and discomfort, as well as when they are calm and content. This, combined with your natural intuition as a parent, will help you to help the doctors and nurses. Together, you can tell when your baby might need some intervention.

As well as medications, your baby's symptoms can be soothed by gentle massage or comfort holding. Your care team can support you with this.

Taking your baby out

If your baby is able to leave the neonatal unit for periods of time, you may have the opportunity to spend time with your baby outside, perhaps in the hospital grounds. Seeing your baby out in a pram feeling the air on their skin can be a special experience.

Reading and singing with your baby

Reading a story, playing music or singing songs that are special to you can really help you to bond with your baby.

Capturing special moments

Special moments with your baby will stay with you forever. Capturing these lasting memories, from finding out you are pregnant and throughout your baby's precious life, can be done in a number of ways:

- Taking photos
- Taking a small lock of hair
- Make handprints and/or footprints
- Make hand or foot sculptures
- Skin-to skin contact
- Playing special music
- Keeping special toys, jewellery or ribbons
- Keeping a keepsake box with cot cards, name bands,
- Having a blessing performed
- Introducing your baby to friends and family
- Keeping a journal

Spiritual and psychological support

Many parents find it helpful to talk to the hospital chaplaincy service – they are experienced at providing emotional and spiritual support, for people of all faiths and those with none. Psychology and Family Support workers can also offer support. These teams can help you talk about your concerns, think through big decisions and advocate on your behalf if you would like help in getting your views across.

Finding out your baby has an uncertain future

You may have been told that your baby has a life-limiting condition while you are pregnant or after your baby has been born. Your baby may not have been diagnosed with a specific condition, but there will be a view from the care team that your baby's health problems are worrying and their future is uncertain. For some, this prognosis will mean your baby has a very short life. For others it can be less certain and your baby may live for days, weeks or years, perhaps with complex care needs.

You may have twins or triplets and have found out that one or more of your babies has a condition that means they will die later in the pregnancy or shortly after the birth.

It can be difficult to take in and make sense of the information you are being given and the decisions you might have to make. You should expect to be fully informed about your baby's condition, even when their prognosis is uncertain, and be given plenty of time to ask questions.

Your care team should make sure that you understand what the prognosis means and the decisions that you may have to make. Interpreters should be available if English is not your first language. This may take some time to be organised, so do ask if English is not your first language and you need help to understand. Above all, you should always be treated with respect, honesty and sensitivity at this difficult time.

What to expect when you find out your baby has an uncertain future and needs palliative care:

1. To be treated with openness and honesty.
2. To be supported to become experts in the care of your baby.
3. To have conversations with your care team in privacy and with time to ask questions.
4. To be able to have these conversations together with both parents, or with another family member or friend – if this is your choice.
5. To be given information that is easy to understand.
6. To be able to record the conversation so that you can listen to it again; or to be given the information in writing.

Palliative care

Your team may have talked to you about palliative care for your baby. This can be a scary term, but actually palliative care is about providing the best possible comfort and quality of life for a baby, however long they are with us, whether that is a short time, or even for many years.

It is about managing a baby or child's pain and symptoms, but also about supporting the whole family by providing emotional, spiritual and practical support throughout their life. Palliative care can be delivered throughout their life by a range of different professionals at home, in hospital or in a children's hospice.

Palliative care can be provided by all healthcare professionals and members of your neonatal unit care team should be able to support you and your baby through your palliative care journey. Sometimes, a children's hospice or palliative care team will be available to support you alongside the team that has been supporting you in the neonatal unit.

A palliative care team can be based in the hospital, in the community or as part of a children's hospice. They will have specialist knowledge in managing any symptoms your baby may have and in supporting your family through your baby's life and into bereavement. They can provide ongoing support to you and your whole family. It may be helpful to talk to a member of staff from your local hospice or palliative care team early on. They can talk to you about the kind of support that they can offer and the options available to you.

Some children's hospices have dedicated perinatal or neonatal link nurses who can support you and be the link between the hospice and your hospital. Please speak to a member of your baby's team if you would like to arrange a visit to your local hospice to see what it is like or be shown a video tour. You can find more information about hospice and palliative care teams on page 12.

Parallel planning

It may be that your baby's prognosis is unclear and that it's suggested you plan both for their ongoing care needs and for their end of life. This planning, for both possible outcomes, is sometimes called ‘parallel planning’. It means that we are hoping for the best whilst also planning for the worst case scenario so we then have a plan in place for both scenarios. For example, if your baby lives longer than expected, as well as for their death.

Advance Care Planning (ACP)

An Advance Care Plan (also called an Anticipatory Care Plan or Future Care Plan depending on where you are based in the UK) is a care plan that sets out agreed actions to be followed if or when your baby’s condition gets worse. The ACP will be specific to the needs of your baby and your family. It can be shared with all professionals involved in the routine care of your baby as well as those who might be called in an emergency. This means that everyone has clear information about your wishes and needs. Advance Care Plans should be reviewed regularly to ensure that the plan of care is still appropriate and that everyone remains in agreement.

An Advance Care Plan may include the following elements:

- Symptom management plan
- Discussions about your preferred place of care (home, hospice or hospital)
- A plan for your baby’s end of life care
- Discussion about organ and tissue donation
- Discussion about post mortem

Decision-making

Making decisions which influence your baby’s care and treatment can be difficult. Your baby’s neonatal team is there to support you through the choices to be made. You should be included in all discussions about your baby’s care so that you can understand the implications of the decisions that need to be made. This means that doctors should invite you to be present and to take part in the discussion when they are on the neonatal unit reviewing your baby.

ARC: Antenatal Results and Choices offer impartial information and support to help decide on your next steps in making antenatal decisions.

Together for Short Lives has produced several resources around supporting parents including information around choices of care.

Seeking a second opinion

It can be very difficult to know the best thing to do when your baby does not have a firm diagnosis or a clear prognosis. You have the right to seek an external second opinion about your baby's prognosis and/or potential treatments as it can help you and your care team understand more about your baby's condition and what treatment approaches would be in their best interests.

If this is something you would like to explore, please do speak with your care team and they can help and support you through this.

Please remember, you do not need to undergo this difficult and challenging time on your own. Hospital, community and hospice teams (be it healthcare, chaplaincy, psychology and/or family support workers) are there to help, support and guide you when and wherever you need them.

For supportive information for families about seeking an external second opinion, visit The Royal College of Paediatrics and Child Health (RCPCH) website.

All website links can be found at the back of this booklet.

Ongoing care

Depending on your baby's condition, your care team may talk to you about their ongoing care and where this will take place. You may wish to stay at the hospital where your baby has been looked after since they were born, you may be able to take your baby home, to a hospital nearer to your home, or to a children's hospice.

You will first need to plan with your care team about the transfer to your chosen place to ensure that your baby will be medically fit to travel and is kept as safe and comfortable as possible on the journey.

If it is possible and you would like to take your baby home, it will be important that all your needs are assessed so that any appropriate medical and nursing support can be put in place. There may be a community children's palliative care team available to support you at home. These teams come in different forms and can provide care in different ways, with doctors, nurses, pharmacists and family support workers as part of the team.

Children's hospices

As described earlier, you may have met with a member of a local children's hospice team on the neonatal unit and already have a good knowledge of how the hospice can support you.

Children's hospices can provide ongoing care for your baby and emotional, social and spiritual support for you and your family. Children's hospice services can deliver this care in a purposebuilt building and/or in the home (commonly called 'hospice at home').

Services may vary from hospice to hospice, but can include:

- Support for the entire family (including siblings, grandparents and the extended family)
- End of life care and use of a cool room or cooled cot; also known as a cuddle cot.
- Practical help, advice and information
- Specialist short break care
- Specialist therapies, for example, physiotherapy, hydrotherapy, play and music therapy
- Bereavement support
- Provision of information, support, education and training where needed for parents or carers

You can find information about individual hospices local to your area via the Together for Short Lives website.

End of life care

It is not always easy to predict the time when your baby is likely to move into the final phase of their life. For some, it may only be realised hours or days before, which can leave very little time to prepare for your baby's death.

You should ideally already have had early 'parallel planning' discussions with your team and developed an Advance Care Plan which includes your wishes for your baby's end of life care. This can be difficult if your baby's condition deteriorates quickly, but you should be fully supported to develop an end of life care plan for your baby that identifies all your wishes and how these will be met.

If your baby dies in hospital, there should be a quiet room that is private, away from the other rooms on the neonatal unit, where you can spend time with your baby, family and friends, with a cuddle cot. A cuddle cot is a cold mattress that ensures that your baby remains cool, so that you and your family can spend time with them and enables more time to create memories. The cooled mattress can be put into any Moses basket or cot, can be placed in bed with parents, or even in their arms.

You may choose to take your baby home from hospital after they have died and you should be able to access a cuddle cot from a local children's hospice or your hospital or community palliative care team. You may also be able to take your baby to a children's hospice cool room where they can stay until their funeral or before being taken to a funeral director.

This is also a time when you might to continue to capture special moments and create lasting memories. You may wish to:

- Have skin-to skin contact
- Play special music
- Take a small lock of hair
- Make handprints and/or footprints
- Make hand or foot sculptures
- Keep special toys, jewellery or ribbons
- Have a blessing performed

Your care team within the neonatal unit or a member of the hospice/palliative care team will be there to support you throughout your baby's end of life care. Remember, you will not have to do any of this on your own.

The 'Get Support' section of the Together for Short Lives website provides useful information regarding ongoing support from children's palliative care services, including care at the end of life.

Child Bereavement UK's website also offers lots of support and includes some short guidance films.

Bereavement support for you and your family

Services that have supported your family are best placed to discuss what type of bereavement support is available. Whether it’s counselling, therapies or spending time to remember your baby as a family, do allow yourselves to take time out of everyday life and share how you are feeling.

What bereavement support is available?

Bereavement support after your baby has died can take many forms. Sometimes the best support can be someone’s practical help or a friend just being there to listen. You may find that you need extra support, which can be provided by a range of professionals, charities, hospices and parent support groups. Bereavement support is important for your whole family, including siblings.

Your care team will be able to advise you regarding bereavement support available locally and signpost you accordingly.

What should I say to my other children?

Grief will affect children in many ways depending on their age, experience and relationships within the family. Letting siblings know what is going on and actively involving them in what is happening can help them to cope better. It is usually best to be as clear and honest as possible, saying that their brother or sister has died so that they don’t misunderstand what you are saying.

Winston’s Wish provides emotional and practical bereavement support to children, young people (up to 25) and those who care for them.

How do I tell people that my baby has died?

There will be lots of people to inform that your baby has died - extended family, friends, colleagues. You might want to think about asking a close friend or member of the family to take on the role of sharing the information so that you are not bombarded with well-meaning questions. You can ask for a member of your care team to help with sharing the news.

Planning your baby's funeral and celebrating their life

Planning for your baby's funeral, or service of remembrance, is very important for most parents as a way of celebrating your baby's life. There are many ways in which you might choose to remember and celebrate your baby, with carefully chosen words, songs (or hymns) and readings, flowers and candles.

Siblings can also find it helps them to feel involved if they can participate in funeral planning and saying goodbye in a way that is meaningful to them. If you need any help with this please speak to a member of your care team or the funeral director who can guide you through the process.

Some ideas for you as a family may include:

- Making a keepsake box
- A balloon or butterfly releasing ceremony
- Writing in a book of remembrance at the hospital or children's hospice
- Placing something in a garden of remembrance or in another special place

Useful resources and organisations that can provide information, help and support

Bliss (UK) Email: hello@bliss.org.uk www.bliss.org.uk	The national charity for babies born premature or sick. For information and support about looking after your baby on a neonatal unit and at home and links to parent peer support groups, you can contact the Bliss support team.
Together for Short Lives (UK) Helpline: 0808 8088 100 Email: helpline@togetherforshortlives.org.uk www.togetherforshortlives.org.uk/getsupport	Together for Short Lives is the UK's leading charity for children's palliative care. For information and support about children's palliative care, including links to parent peer support groups, you can contact the Together for Short Lives Family Support Hub.
ARC: Antenatal Results and Choices (UK) www.arc-uk.org	Antenatal Results & Choices offers impartial information and support to help decide on your next steps in making antenatal decisions.
Child Bereavement UK www.childbereavementuk.org/supporting-bereaved-children-and-young-people	Child Bereavement UK provide support and guidance for all members of the family affected by the death of a loved one and includes some short guidance films.

The Children's Funeral Fund for England www.gov.uk/child-funeral-costs	The Children's Funeral Fund for England can help to pay for some of the costs of a funeral for a child under 18 or a baby stillborn after the 24th week of pregnancy.
Contact (UK) www.contact.org.uk	Providing information and details of condition support groups for families with disabled children. Contact offers support to families, brings families together and helps families take action for others.
Held In Our Hearts (Scotland) www.heldinourhearts.org.uk	A Scottish-based charity providing baby loss counselling and peer support to families.
Royal College of Paediatrics & Child Health (UK) www.rcpch.ac.uk/resources/exteranalsecondopinions	For supportive information for families about seeking an external second opinion.
Sands (UK) www.sands.org.uk	Sands offers support to anyone who has been affected by the death of a baby before, during or shortly after birth, whenever this happened and for as long as they need support.
Simba (Scotland) www.simbacharity.org.uk	SIMBA help those grieving create precious moments to honour their babies memory.

Sunbeam (Wales)	Sunbeam is a partnership of health care professionals from across specialist antenatal, neonatal and palliative care services offering support to families in Wales where there is uncertainty about their baby's future. Your local team will be able to support you being referred to this specialist team.
Tommy's -The Pregnancy Charity (UK) www.tommys.org	Tommy's is dedicated to finding causes and treatments to save babies' lives as well as providing trusted pregnancy and baby loss information and support.
Twins Trust (UK) www.twintrust.org	Aiming to facilitate a network of community support, Twins Trust provides parents of twins, triplets or more, information and guidance as well as helping to ensure these families' unique needs are understood by the professionals who care for them.
Winston's Wish (UK) www.winstonswish.org	Winston's Wish provides emotional and practical bereavement support to children, young people (up to 25) and those who care for them. They also have publications available to order offering support for children when someone close to them is seriously ill.

With thanks to the following for generously funding this resource

The Michael and Anna Wix Charitable Trust

COMMUNITY
FUND

JAMES TUDOR
FOUNDATION

HSF
The Hospital
Saturday Fund

Fairy Water Trust

Bliss
for babies born
premature or sick

bliss.org.uk

together
for
short
lives

togetherforshortlives.org.uk