

A Perinatal Pathway for Babies with Palliative Care Needs

Second edition 2017



A Perinatal Pathway for Babies with Palliative Care Needs, 2nd edition
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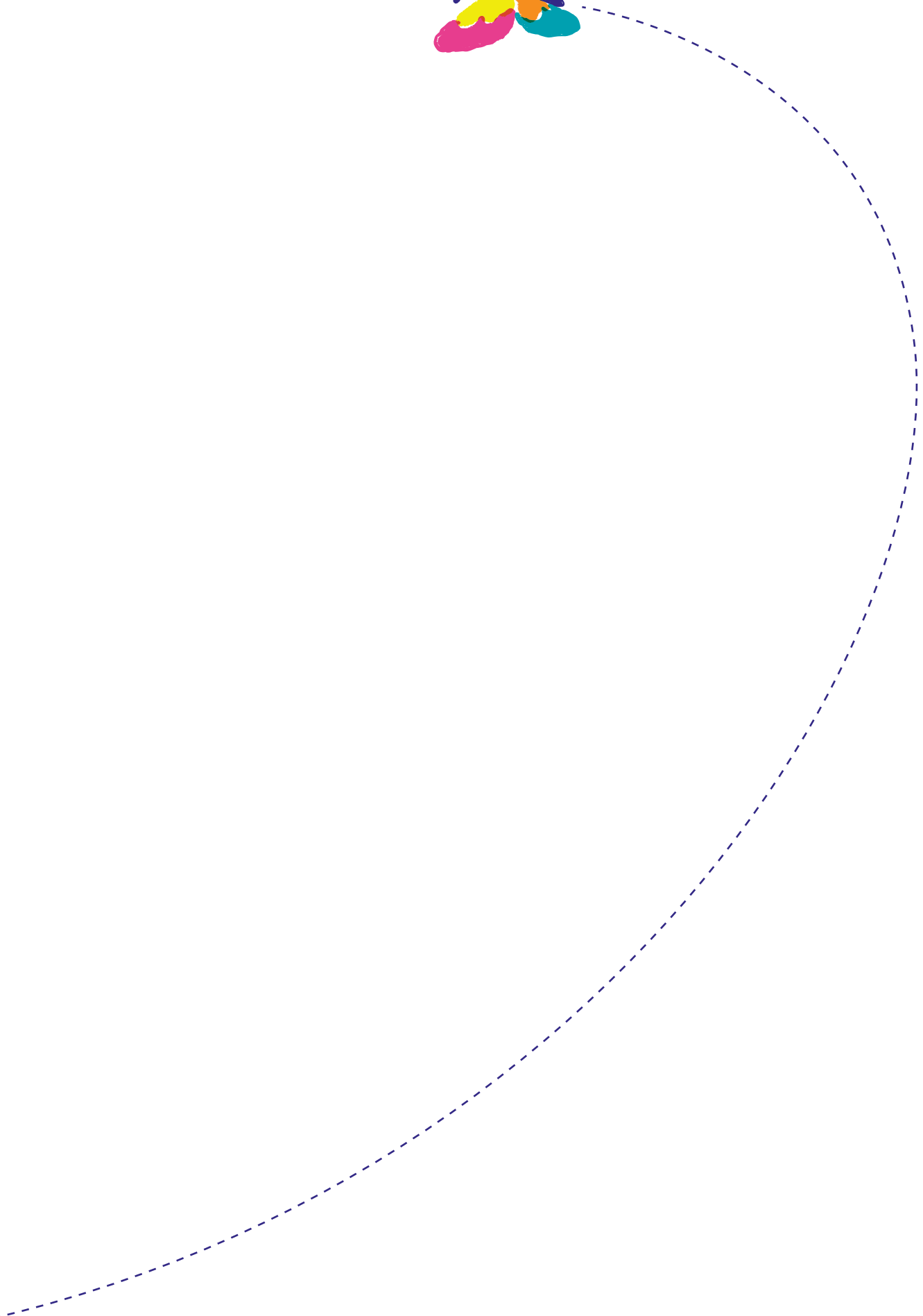
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This publication will be reviewed on an annual basis and amended as needed, at our discretion.



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About Together for Short Lives

49,000 babies, children and young people are living in the UK with health conditions that are life-limiting or life-threatening – and the number is rising, particularly in those under one year old. Hearing the news that your baby or child has a life-limiting condition and is likely to die young is devastating.

It can be an incredibly distressing and confusing time. Many will have complex and unpredictable conditions and need round the clock care, seven days a week. Families must cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services offering help, these families still face challenges in getting the right care and support.

Together for Short Lives is a UK wide charity that, together with our members, speaks out for all babies, children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Together for Short Lives supports parents so they know where to go for the most relevant information and have the information to help them make the right choices about their child's care. We are here to help families access the support of palliative care services, when and where they need it.

Together for Short Lives supports all the professionals, children's palliative care services and children's hospice services that deliver lifeline care to babies, children and families across the UK.

Together for Short Lives has over 1000 members – individuals, teams and organisations interested in and committed to supporting babies, children and young people (and their families) with life-limiting conditions. These include children's hospice services, voluntary sector organisations and statutory service providers. By working together, we will drive change so families don't have to keep struggling to get the care they need.

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Forewords

by **Caroline Lee-Davey, Bliss** and **Julia Samuel, Child Bereavement UK**



Bliss
for babies born
premature or sick

The death of a baby, whether during pregnancy or in the first days, weeks or months of life, is a tragedy.

The loss of a much-loved and much-wanted infant represents not just the loss of a life, but the loss of a family's hopes and dreams for the future. It is therefore vital that all perinatal services deliver sensitive and high quality care to support both babies and their families during this period: to support informed decision-making in the baby's best interest; to ensure that babies are afforded the utmost dignity and respect in all aspects of their care; to make the most of the time that babies and families have together; and to help families make lasting memories of their loved one which can, in some small measure, help their grieving process after death.

On behalf of Bliss, the national charity for babies born premature or sick, I am pleased to welcome and support this updated care pathway for babies with palliative care needs. While the vast majority of the more than 90,000 babies admitted to neonatal care each year recover and are discharged home, just over 2,000 babies die from causes likely to require palliative care. We also know that over recent years, children's hospices and other palliative care services have found themselves supporting an increased number of neonates with life-limiting conditions, so this pathway is very timely.

Importantly, this pathway is grounded in the Together for Short Lives core principle that "parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their baby". While every baby and their family's journey will be different, this is the thread that binds all their experiences together, and is at the heart of how everything in this pathway should be read and applied in

practice: every communication, every decision, every care plan, and every service.

I hope that you find this updated pathway a useful tool to review your own services, to identify and address any gaps, and, where needed, as leverage to secure support from your trust and commissioners to ensure that the highest quality service can be provided to all babies needing palliative care, and their families. I also hope that it serves as a valuable and practical resource to support the education and training of all professionals who deliver perinatal care and may therefore play a role communicating with and delivering palliative care services to babies and families. I look forward to continuing to work with all of you, alongside Together for Short Lives, to ensure that each and every baby, and their family, receives the excellent care that they deserve.

A handwritten signature in black ink, which appears to read 'Caroline Lee-Davey'.

Caroline Lee-Davey
Chief Executive, Bliss



I am delighted to see this updated pathway which clearly sets out the needs of families at such a difficult time in their lives and how professionals can help them get the support that they need.

I am particularly pleased to see that it recognises that grief starts at the point of diagnosis and that it acknowledges the ongoing training and support needs of the professionals involved in this work – if they are to do it effectively.

This pathway will also be a relevant resource for commissioners of services to ensure that the appropriate care is available in the right place, at the right time and delivered by the right people.

I have seen that perinatal palliative care is often provided in a busy and intensive care environment where the baby's condition and prognosis may change suddenly – I believe this pathway will provide a framework for good practice so that along with the 'noise', families get the support that they need to be active in their baby's care and make the best memories they can, even if their time together is short. The principles of good care and support shine through regardless of the location of care of the baby.

I am very happy to endorse this updated pathway by Together for Short Lives and hope it will be used widely and effectively.

Julia Samuel MBE
 Founder Patron, Child Bereavement UK and
 author of *Grief Works: Stories of Life, Death and
 Surviving*



The need for palliative care may be recognised during the pregnancy, at the prenatal 20-week scan, or may not become apparent until after a baby is born.





Introduction

This is the second edition of the Together for Short Lives dedicated care pathway for young babies who may need palliative care.

The majority of child death happens in the first 28 days of life, the neonatal period. Every year, over 90,000 babies (Bliss, 2017) are admitted to neonatal intensive care in the UK. While many of these babies will only need to receive treatment for a few days or weeks before being discharged home, a minority will need more intensive care.

On average, there are 2,109 neonatal deaths each year from causes likely to require palliative care (Bliss and Together for Short Lives, 2012) and currently 98% of these deaths occur in a hospital setting (ACT, 2009).

Together for Short Lives has recognised the need for a dedicated perinatal care pathway from the point of recognition that a baby may not survive for long after birth and through their neonatal period. The need for palliative care may be recognised during the pregnancy, at the prenatal 20-week scan, or may not become apparent until after a baby is born.

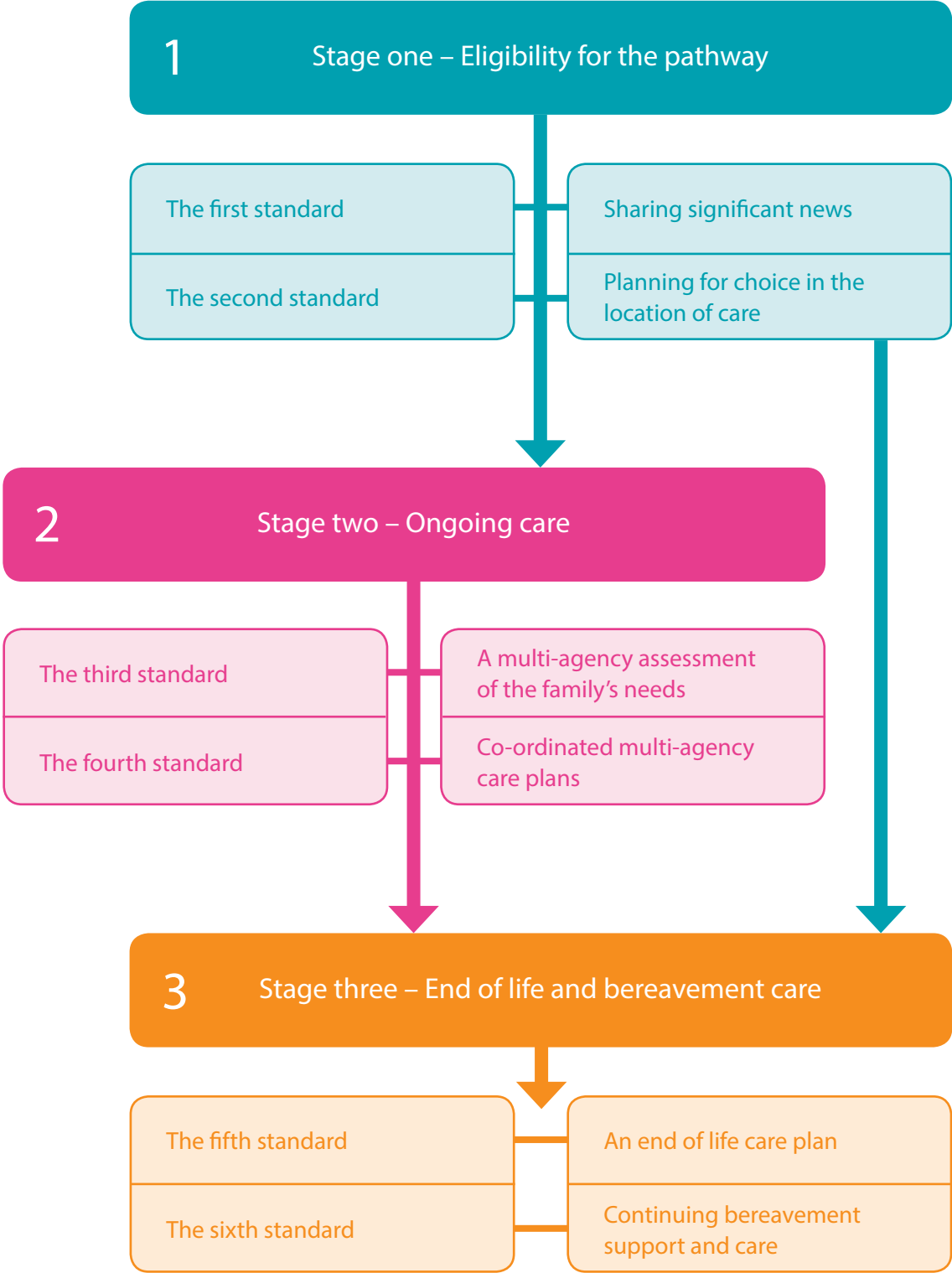
This Perinatal Pathway for Babies with Palliative Care Needs will be of interest to fetal medicine specialists, obstetricians, neonatal service providers, maternity services, including midwives and those working in the children's palliative care sector. It is also a resource that can be used by commissioners of services to ensure that the appropriate care and resources are available in the right place, at the right time and that care is delivered by the right people.

The emphasis throughout the document is that involving professionals working together across multi-disciplinary teams and services will provide the best response to families during a distressing and uncertain time.

This pathway is one of a suite of care pathways from Together for Short Lives which includes the Core Care Pathway, the Extubation Care Pathway and Stepping Up – a revision of the former Transition Pathway.

Together for Short Lives hopes that this updated and extended care pathway will be a tool to encourage professionals working within fetal, maternity and neonatal services to offer families timely choices in their care and to enable families to have the best possible experience and memory of their baby, no matter how short their life may be.

Perinatal Pathway for Babies with Palliative Care Needs: summary diagram



The Together for Short Lives care pathway approach

The first edition of the Neonatal Care Pathway was published in 2009. The second edition has been updated to reflect the fact that palliative care is increasingly being introduced antenatally as well as postnatally. For this reason, Together for Short Lives has recognised the need for a dedicated perinatal care pathway from the point of recognition that a baby may not survive for long after birth and through their neonatal period. As with all our pathways, it aims to provide an overarching framework which can be used to develop detailed pathways which reflect local service provision.

It is consistent with the National Institute for Health and Care Excellence (NICE) guidance on end of life care for infants, children and young people published in December 2016 (see Appendix 1).

Local resources

It is vital to understand the local resources available to families. This will vary and it will be important to only offer what can be delivered in the local area, for example, taking account of the details of the designated neonatal transport team and what local hospice or palliative care teams are and are not able to offer.



About children's palliative care

Together for Short Lives' definition of children's palliative care:

Palliative care for babies, children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life and death. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The Together for Short Lives' approach to children's palliative care states that:





- Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.
- Child-centred care will be provided whether the family are in hospital, the family home or a hospice environment. The family home shall remain the centre of caring whenever possible, if this is what the family want.
- Care away from home should be provided in a child-centred environment by staff trained in the care of children, with the needs of siblings taken into account.
- Every family shall be given the opportunity to have consultation with a specialist who has particular knowledge of their child's condition.
- Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.
- Professionals providing care for children with life-limiting illnesses should receive specific training in palliative and end of life care and in communication skills.

These principles will apply to neonates as well as older children. In perinatal palliative care, the support is more likely to be received in a hospital setting from neonatal staff.

Together for Short Lives has developed a well-established categorisation of conditions which sets out four broad groups of life-threatening and life-limiting conditions (see glossary) and their different illness trajectories. These four categories of illness trajectory are outlined in the diagram below with examples of the types of conditions in the perinatal period that may be included in each. The categorisation is important for planning and needs assessment, but it's important that the need for palliative care should always be assessed on an individual basis and frequently reviewed as needs may change rapidly depending on the clinical course of the child's illness. Regular review of plans both antenatally and postnatally is essential. It should be remembered that such categorisations are not black and white and that the examples used are not exclusive.

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail</p> <p>Provision of palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: extreme prematurity, severe necrotising enterocolitis, congenital heart disease.</i></p>
Category 2	<p>Conditions where premature death is inevitable</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Example: chromosomal abnormality, severe spina bifida, bilateral multi-cystic dysplastic kidneys, bilateral renal agenesis.</i></p>
Category 3	<p>Progressive conditions without curative treatment options</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Example: anencephaly, skeletal dysplasia, severe neuromuscular disorders.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death</p> <p><i>Example: severe hypoxic ischaemic encephalopathy.</i></p>

Together for Short Lives has also developed a set of diagrams which illustrate the various patterns of relationship between palliative care and treatments aimed at cure. Perinatal palliative care is an approach to care which can be used exclusively or in conjunction with curative treatments, using a parallel planning approach.

Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
<p>Key: curative palliative</p>	

Perinatal palliative care

When parents find out that they are going to have a baby, this time of their lives should be filled with hope, optimism and anticipation of the life that is going to join theirs. When parents receive devastating news about the health of their unborn baby, have a premature delivery or a perinatal event, the toll this takes on the family is immense and their grief and sense of loss will begin at this point.

Palliative care for babies is particularly challenging for a number of reasons. Firstly, diagnostic uncertainty is a significant challenge in perinatal palliative care, it is often the case that the underlying diagnosis is unclear, whilst the overall prognosis is better understood. Care may be being planned for a baby who is not yet born and care is often provided in a busy and intensive care environment where the baby's condition and prognosis may change suddenly, meaning that often families do not have time to plan for these changes.

The time parents have to spend with their baby can be very short and therefore very precious – if it is missed it is gone forever. One key aim of perinatal palliative care is to enable families to have no regrets about how they spend this time.

For multiple birth pregnancies, the mother may have one or more sick babies to care for alongside babies who do not have a life-threatening condition. The baby's mother may have health needs of her own. Some women, such as those with pre-eclampsia may be seriously ill themselves. Partners' needs are significant as they often struggle to take in information and feel very torn between the needs of their baby and their partner.

There are often multiple teams and services involved, sometimes in different hospitals and so there is a need for good communication and to include transport services in care planning. The speed at which babies deteriorate and die can appear to be much faster than in older children. This may be due to factors such as delayed diagnosis or death from withdrawal of life-sustaining treatment which can make death seem to happen very suddenly. There is a smaller window of opportunity for carrying out parallel planning and introducing effective palliative care support for newborn babies.

There are limited opportunities for parents to make and share memories of their baby. The grief that ensues can therefore be lonely, with few people having met their baby if they die very soon after birth. There can be a lack of appreciation of what has happened from their usual support circles. Parents can feel loss even in the absence of death, such as in the loss of an anticipated pregnancy course. Bereavement support therefore needs to start from the time of recognition that the baby or unborn child has a life-limiting condition. Grandparents often have a significant role to play in supporting their child and other members of the family.

The focus of this pathway is on enabling families to spend time with their baby, bonding and building memories, in a more home-like environment, and with as little technology dependent care as possible. There is more emphasis on family-centred care to enable parents to create positive memories, for example through having time to hold their baby. Professionals working in antenatal and neonatal services are accustomed to providing babies and families with sophisticated expert care using high levels of technical skills, communication and knowledge. There is a growing need for them to provide a palliative care approach as technology allows more accurate prenatal diagnosis of conditions that are threatening to the baby's life. The environment within neonatal units can foster a dependency on technology and equipment. A palliative care approach throughout the pathway means a shifting of emphasis, ensuring that the baby continues to receive intensive care but with a reducing level of highly technical care.

Overarching principles of the Perinatal Pathway for Babies with Palliative Care Needs

There are a number of overarching themes which should be considered at every stage of the care pathway – from recognition that the baby may have a life-limiting condition, to the baby's death and ongoing bereavement support to the family.

Ability to respond quickly

The majority of babies who die will have a very short time to live and the normal planning meetings and appointment of key workers may not happen. Nevertheless, it is vital to remember the importance of talking to parents and other family members, giving them choices in as timely a manner as possible. If they choose that their baby dies at home or at a local hospice and this is a realistic option for them, then the pathway should be followed to support the baby's discharge from hospital if possible. It is also possible that a baby is born with significant health needs at home and this situation will also need a rapid response from midwives and emergency services.

Bereavement support for families

Providing details of sources of support at the earliest possible stage is beneficial to families who often feel a sense of isolation in these early days following the starkness of a diagnosis. Bereavement support should be provided from the time of recognition of a life-limiting illness and continue throughout the baby's life, during and after their death. It is important to remember that families are all different in the way that they find support. Mutual help such as support groups suit some, but not all. For some families, couple support can help them to discuss the strain on their relationship that can come from caring for a dying baby. Other families, such as those where the parents are very young, or where there is a lone parent, may need extra support. There should be an individual assessment of what will be beneficial to individual families and signposting to what is appropriate.

Best interests and decision making about treatment options

For babies with life-limiting conditions, some medical treatments may do more harm than good, or may not be beneficial. It is vital that professionals identify these and either avoid starting or avoid continuing them. Other medical treatments may be more appropriate and helpful (particularly those providing relief from distressing symptoms). Decisions about treatment options should be made with families and adjusted as the baby's condition and needs change. The overriding legal and ethical principle is that all treatment decisions must be taken in the baby's best interest post their birth. It should involve decision makers with relevant areas of expertise, and balance all relevant factors in order to assess the best option for the individual. It is a fundamental principle of the United Nations Convention on the Rights of the Child.

Communication

There should be an honest, open and timely approach to all communication with parents and carers who should be treated as equal partners in any discussions with the care team. It is crucial to remember the importance of talking to parents and the family, giving them choices and maintaining a flexible, 'can-do' attitude to support their choice. If they choose to allow their child to die at home, or at a local children's hospice, then wherever possible the pathway should be followed to support the child's rapid discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, so they can act as the family's first point of contact for communication, and to ensure that information flows to all services.

Diversity and cultural factors

Culturally appropriate care helps to maintain the quality of family-centred care and to address specific cultural practices around death, dying and bereavement. It is important not to make assumptions and to recognise individual need. It is helpful for staff to have some knowledge of the beliefs and rituals associated with death and dying within different faiths, particularly in relation to issues immediately following death and in care of the body (Children's Hospices UK, 2009).

Some parents or carers can find it reassuring and helpful to discuss their beliefs and values, but remember that some may find these discussions difficult or upsetting. There may be differences in these discussions within each family and indeed between the mother and father (Mancini et al, 2014).

Key point of contact

If the baby leaves hospital there are likely to be several agencies involved in the baby's care. A key working principles approach should be in place where one agency takes a lead role. This key point of contact would be a person who the family would get to know well and who would have local knowledge and expertise. Sometimes there will be a small group of key professionals and the individuals involved may change depending on the baby's condition, progress or care setting.

Medical lead

There should be a named specialist for each phase of care, who might be a neonatologist, paediatrician or children's palliative care specialist. There must be clarity about who this medical lead is for families.

Multiple admissions

Babies with life-limiting or life-threatening conditions often experience multiple admissions to hospital and it is helpful to prepare the family for the possibility that their baby may be admitted to a different hospital, under a different care team.

Multiple losses

When a family loses a baby, they can experience repeated bereavement; first the loss of the pregnancy and the hoped-for baby they were expecting, followed by the anticipated then actual loss of their baby. At times, a baby may defy medical expectations and survive, only for the family to then have to face their death in future years. Some families may also experience the death of more than one child with the same condition. This is particularly common in families who have multiple births.

Parallel planning

This is the process of planning for ongoing care alongside planning for end of life care. It takes account of the often unpredictable course of conditions and involves making multiple plans for care, and using the one that best fits the baby's circumstances at the time (NICE, 2016).

Parallel planning before birth prepares the family for what may happen during pregnancy and post-delivery and allows them the opportunity to truly explore their wishes in a variety of circumstances. Planning for the future at times of great uncertainty can also be comforting for families who may feel they are enabling their baby's full potential to be best achieved. This can be a helpful way of working with parents and helping them manage their hopes for care, live with uncertainty and make plans (Brecht and Wilkinson, 2015).

For some babies, survival into early childhood is unlikely, but possible. There may be periods where the team feel end of life is imminent, but the baby may survive. It is important that proactive parallel planning is practised, delivering end of life care as required but continuing to plan and make available the full range of support from local services where possible.

Postnatal care of the mother

The baby's mother will also be in need of care and support either in hospital or at home. This is a statutory service provided by midwives and might include, for example, wound care following a caesarean or providing support with expressing milk. Some bereaved mothers may find it upsetting to see the midwife who was supporting her prior to the diagnosis, so this could be talked through with them. Others may find the continuity of care comforting. It can also be challenging to the continuity of care if her baby is at a different trust to the one in which she received her antenatal care.



Psychological support

Every family should be offered emotional or psychological support to meet their individual needs. Ideally, this should begin at diagnosis and continue throughout the baby's lifetime, death and in bereavement. Families should be able to access support when they want to, rather than having their needs assessed at pre-set times.

Siblings and extended family

The specific needs of siblings should be considered throughout the care pathway and particularly while their baby brother or sister is in critical care. It may be appropriate to refer to children's palliative care services which provide sibling groups and activities. More frequently now schools are in a position to support siblings through the use of dedicated and specialised counsellors based within the school setting. Siblings, grandparents and other relatives/ carers, where appropriate, should be included in discussions and planning for the baby's care.

Social care support

Families may have specific needs for social care support, for example, information about practical considerations including benefits or maternity and paternity rights or hospital parking.

Palliative care social workers will often use a psycho-social approach to advocate for families, working as a critical link between the information and practical support that's available to families caring for a baby with a life-limiting condition. Along with other health and care professionals, they may also have a role in the safeguarding of babies, ensuring that they are being cared for safely and effectively.

24 hour support at home

If a family is discharged home with their baby, they should have access to flexible support, and be in the care of their GP or a community paediatrician who should have access to 24 hour telephone support from a multi-disciplinary children's palliative care team. The family may also need access to 24 hour care from community children's nurses.

Case study 1:

Nadia's story, shared by Mum Ana

"There is no easy way to say this, but your baby is very, very sick." I was 37 weeks pregnant, and they had just found our baby had severe dilated cardiomyopathy. The doctor thought she would die within days.

We met the palliative care doctors at our next appointment. They listened to our story and wanted to get a sense of 'us.' Then they asked us questions including:

"What would you like to happen?"

"What do you fear most?"

"And what would you like to know?"

I desperately needed to know all the details especially what she would look like when she was born, if she wasn't alive.

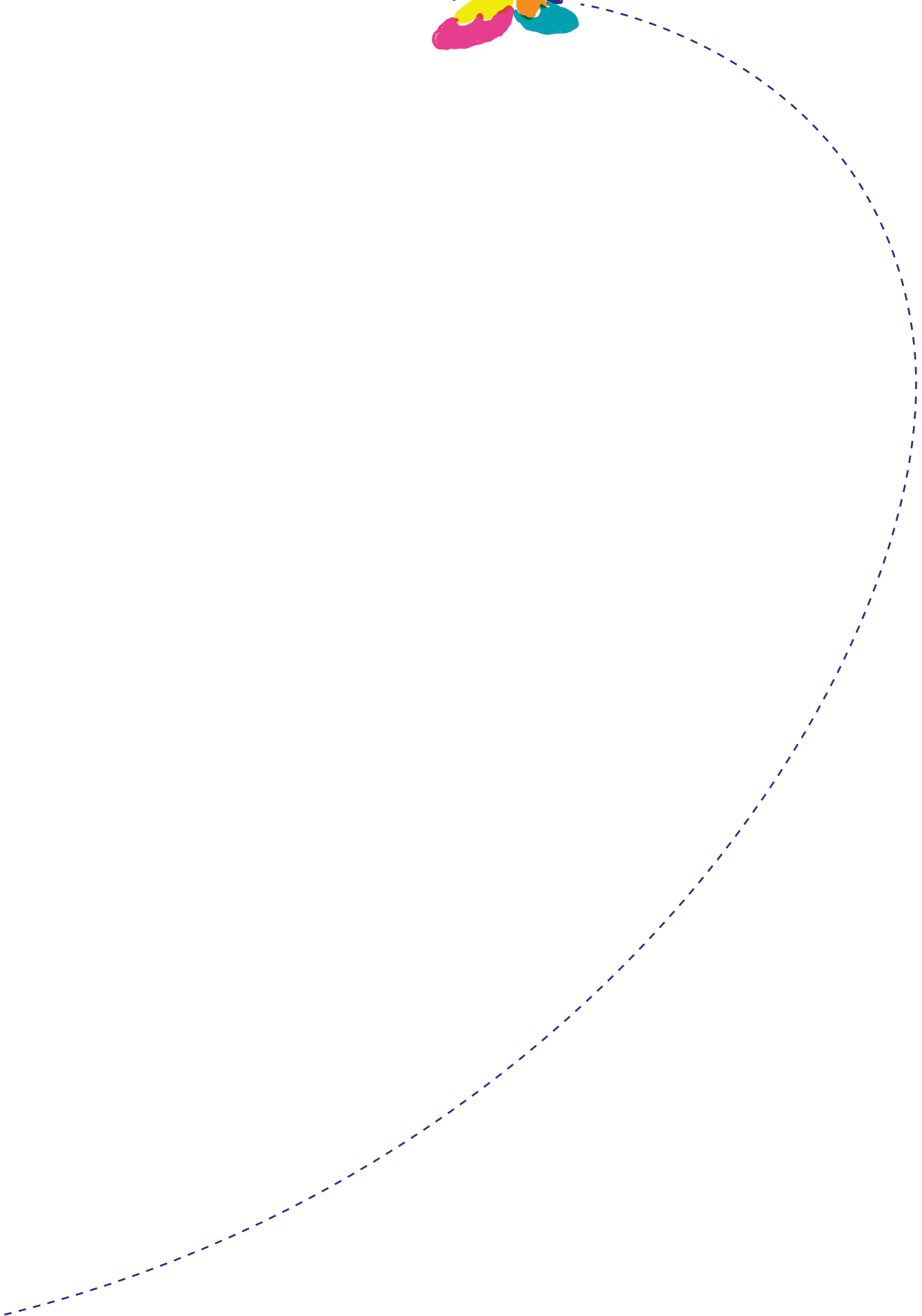
One of the doctors echoed my words back to me before responding. Then he slowly, gently, answered. She would be swollen, especially her

belly, but she'd otherwise look like any other infant. She might not breathe once the umbilical cord was cut. She might not survive the delivery. His words were precise, straightforward, no nonsense, and his approach soft, and this combination resonated with our need to know things, but at the same time to be sheltered from the blows of this knowledge.

Both doctors referred to our baby Nadia by name, showing us they knew how real she was to us.

The doctors were at ease with our tears. In the space of a couple of hours they had transformed what we were going through from something dreadful to something potentially meaningful.

Nadia died a week later, minutes before she was born. But I was braced for it, and I spent the time after delivery holding her while she was still warm. I got to know my daughter as much as anyone could have known her, and this meant the world to me.



While certain conditions may be confirmed antenatally and have a clear prognosis, for others, there may be some uncertainty around diagnosis or prognosis.





Stage one: Recognition of a life-limiting condition

The start of the journey is when it is first recognised that the baby may have a life-limiting or life-threatening condition. This may first be recognised during the antenatal period, or during or following the birth of the baby. The recognition may be triggered by a professional or parental concern or a critical event after birth.

Antenatal or postnatal diagnosis can be made by genetic testing, radiological investigations including postnatal echocardiography or other investigations, for example, antenatal MRI. While certain conditions may be confirmed antenatally and have a clear prognosis, for others, there may be some uncertainty around diagnosis and/or prognosis.

There are a number of situations that may mean that a baby is eligible for the perinatal pathway, for example:

- acute medical condition in the baby, for example, following infection or cerebral haemorrhage
- congenital anomalies which may occur by chance or be inherited through one or both parents' genes. The abnormality could be diagnosed before or shortly after birth, or become apparent at a later stage
- maternal health and environmental factors, which could lead to problems associated with the mother's health whilst the fetus is developing in the womb (for example, infection, alcohol or drugs)
- perinatal trauma including asphyxia
- premature birth
- twin to twin transfusion or if one twin is diagnosed with a life-threatening condition which puts the other twin at risk

The prognosis should be agreed by at least two senior clinicians (for example, a neonatologist and a specialist in the child's condition) and then explained and discussed with the family. If either the parents or staff members are still uncertain about the diagnosis or prognosis, a second opinion, should be offered. If a condition is diagnosed antenatally there may be uncertainty about the prognosis until the baby is born and there is a clearer picture of whether the baby's organ systems can sustain their life.

When a baby has been diagnosed with a life-threatening condition before birth, an early referral to palliative care services can help manage this uncertainty by developing a number of flexible and parallel care plans to manage the eventual outcome.

Whilst for some babies there is a reasonable certainty of death antenatally or soon after birth, there are babies whose prognosis is less clear. They may survive longer than expected with good palliative support or their end of life care phase may extend longer than expected.

Care planning should be continuously reviewed by all professionals, with parallel planning for transition periods into and out of palliative and end of life care.

The first standard: Sharing significant news

Every family should be told, as early as possible, of their baby's diagnosis and prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Early discussions should be encouraged even when the diagnosis is not fully agreed. Information should be provided for the family using language they can understand and by the most senior appropriate clinician available.

Goals in sharing significant news

1. Parents should be treated with openness and honesty.
2. Parents should be supported to become experts in the care of their baby.
3. Parents should be spoken to together if possible, with privacy and with plenty of time taken.
4. Information should be conveyed in a way that parents can easily understand.
5. Parents may find it helpful to record the conversation so that they can listen to it again, or be given the information in writing.

What this means in practice

Hearing that your child has a life-limiting or life-threatening condition and is likely to die is the most devastating news that a parent can hear. Sharing this news with parents is undoubtedly one of the most difficult tasks that any professional will face. Families need honesty, respect and above all, time from professionals disclosing the diagnosis or prognosis. If disclosure is avoided or postponed, parents are likely to discover the truth at a later stage, damaging their trust and confidence in professionals.

Communication

An open and honest approach to communication is important, so that a family's personal views, spiritual and cultural beliefs and values can be supported. Time should be taken to discuss their individual family situation and ensure that

any additional support they might need, such as communication aids or interpreters, is provided. It's important to be sensitive but realistic, giving reassurance when appropriate, but not false reassurance.

Parents may also have preferences for how they would like to involve other people who are important to them, such as wider family (for example, grandparents, siblings) or friends (NICE, 2016).

Information giving is a process not an event. Parents and carers will need more than one opportunity to make sense of the information that they are given and to ask questions. It is important to check whether all family members have fully understood what has been said. It can be difficult for families to take all the information on board when they are in a state of shock and misunderstandings may cause problems at a later stage. Some families find it helpful to record conversations on their phone so that they can listen to them again. Extra support may be needed for lone parents or those with a very limited number of people close to them for support. Parents may want to have a friend or member of their extended family, or perhaps someone from their care team, to act as an advocate for them.

Written information is always valuable as a backup to face-to-face discussion with parents, but it should never be a substitute. Families will often access information via the internet, from books or from other families and may need help with sifting and prioritising this. It can be helpful to provide information about local and national support groups early on so that families can access this support if they wish to.

Practical and financial information should also be made available, for example information about applying for benefits within three months of the baby's birth or details of hospital parking and Blue Badge parking, which can be provided for children under three in certain circumstances. If needed, information about obtaining help with funding a funeral should be given to parents, as there are charities who can help with these costs.

When deciding which professional should lead on communication at a particular stage in a baby's illness, take account of their expertise and ability to discuss the topics that are important at that time; their availability (for example, if frequent discussions are needed) and also the views of the family. It is important to ensure that training and preparation is provided to staff who will have to share significant

news and provide support and care to families at such a distressing time. It can be helpful to use established good practice guidelines for effective communication when sharing news (Together for Short Lives, 2012).

One framework on communication uses the acronym **SPIKES** to help memorise the elements of a Six-Step Protocol for Delivering News (Baile et al; 2000, Sidgwick P et al, 2016).

Step 1: **S**etting up the interview – the more reassured professionals feel about the setting the more at ease and hence available and helpful they will be to the family.

Step 2: **A**ssessing the parent's or family's **P**erception – find out how much they know and in particular how serious they think their baby's condition is and how much it will affect the future.

Step 3: **O**btaining the parent's or family's **I**nvitation – finding out how much they want to know. This is a potentially controversial issue. Guidelines for informed consent indicate providing the information which parents need to make informed decisions. Equally respecting autonomy also means that they have a right not to know or to want to hear information. The challenge in communication is how to know what a parent wants and also how to ensure that there are other opportunities if they decide at present that they do not wish to know all the details.

Step 4: **G**iving **K**nowledge and information to the parent and family. Keep in mind what you want to cover without forging ahead with this agenda ignoring the parents' responses.

Step 5: **A**ddressing **E**motions with empathic responses. People's responses can vary from silence to distress, denial or anger. Acknowledge any shock and ask what they are thinking or feeling. Listen and explore if you are unclear what the parent is expressing and then respond empathically. Empathic reflection lets the parent know you have registered what they are conveying to you in words or body language. Whilst a person is experiencing strong emotions it is difficult to go on to discuss anything further as they will be finding it difficult to hear anything. It is appropriate to allow silence.

Step 6: **S**trategy and **S**ummary. Families will be looking to health professionals for help in making sense of the confusion and offering plans for the future. Identify coping strategies and reinforce them – helping them to prepare for the worst and hope for the best.



The second standard: Planning for choice in the location of care

Where possible, every baby and family should have the opportunity to spend time together as a family in a location of their choosing. If a transfer plan is required, this should be agreed between the family, hospital and community palliative care or hospice teams, with clear arrangements in place for transport between settings.

Goals in planning for choice in the location of care

1. A multi-disciplinary planning meeting should take place as soon as possible.
2. If a transfer is required, a clear plan for this should be agreed with the family, hospital and hospice or community services.
3. Key working principles should be in place so that the family knows who to contact with any query.
4. If the family are to be transferred to a children's hospice, a member of the hospice team should meet the family at the hospital before discharge.
5. All neonatal units should have access to dedicated neonatal transport services through their networks.
6. If parents choose to take their baby home, they should have open access to the hospital day and night and be encouraged to visit the ward where their baby is likely to be readmitted if the need arises.
7. The family should have worked with the care team to develop an Advance Care Plan (ACP) and the family should take this home with them.

What this means in practice

Most perinatal death happens in hospital and this is often where families choose to be – at the hospital cot side where they have known a 'home' together as a family during their baby's short life. For some families it's possible for them to choose to go home, transfer to a hospital more local to home or to a children's hospice if there is one. The choice of location of care needs to be realistic and appropriate for each individual baby and family, so care will need to be taken to fully explore what is available locally. The timing

of discharge will depend on whether hospital treatment for the baby's condition is needed and on the parents' wishes. Privacy and comfort for the baby and the family in their chosen place for care are paramount.

When mother and baby are separated

It can be challenging when a baby is taken for intensive treatment and is separated from the mother. It's even more challenging if the mother and baby are in different hospitals or even different towns. In the case of multiple birth pregnancies, the babies may be at different units or even different trusts if they have different care needs. Clear concise communication across teams will be essential.

The effects of separation can be minimised by sending something smelling of the mother with the baby and, in turn, giving the mother her baby's blanket. This can also be beneficial in helping to bring in the mother's milk if she wishes to express breast milk for her baby. If the mother chooses to express then a pump will need to be provided as well as a separate fridge in which to store the milk.

It can also help if the team looking after the baby keeps a diary of the baby's day which can be shared with the mother. Some neonatal units also use video calling equipment to keep mothers in touch with their babies.

Staff should be mindful of the role of fathers, partners or other supporting individuals. They can often feel 'useless' in this situation and that they are getting in the way, but can in fact play a key role in decision making.

Transport from a neonatal unit to care at home or in the hospice

Taking a baby home with a life-limiting diagnosis, complex medical needs and equipment, can be a truly daunting task. Comprehensive discharge planning is crucial to support a seamless transition to home or other place of care. The mother's own care needs will need to be considered as well as any support the family may need to help them prepare other children for the discharge home. Some hospitals can provide an outreach service which improves continuity of care between settings.

How children's hospice services can help

Some children's hospice services can provide specialist care and support for babies with life-limiting conditions and their families. This support may be available in the children's hospice building or provided by hospice staff at home. In recent years, children's hospices are engaging more with local neonatal units and midwifery care providers to ensure that hospice care can be accessed whilst the baby is in hospital.

Perinatal hospice care is an emerging but incredibly vital service and an increasing number of children's hospices have recruited dedicated neonatal link nurse roles to enable an in-reach service. This model of care ensures that a family are supported from diagnosis (including antenatal diagnosis) throughout the pathway by a dedicated hospice team who works closely with the neonatal unit and midwifery teams. This results in a more consistent and seamless delivery of care. The support offered can include support at scans and fetal medicine appointments; support for planning the delivery, at the time of delivery and care post-delivery.

Where a decision has been made in the antenatal period for a baby to receive palliative care, it may be possible for the local children's hospice to arrange to meet with the parents and invite them to visit the hospice. It is important to find out if this level of service is available in the local area.

If a baby is having life-sustaining treatment withdrawn, a children's hospice can provide a safe setting for this to take place and specialist care, advice and support for the whole family throughout end of life, where privacy and dignity are maintained.

If a baby survives longer than expected, children's hospice services can provide specialist short breaks (respite care) and regular short stays for the baby or for the whole family together. They also provide emergency and end of life care, specialist advice, support for siblings, practical help and information.

A 24 hour telephone support model is offered by many hospice services and an increasing number of services are working together to develop good practice and care in this emerging area of hospice care for babies.

Going home or to a hospice from hospital will require an initial multi-agency needs assessment (as described on page 29).

This assessment should consider whether there are appropriate levels of medical cover available and the training that may be needed for staff in the community so that they can provide the necessary complex care as well as more routine baby care. The assessment will also need to consider issues such as availability of equipment, pharmacy supplies and transport as well as ensure a thorough risk assessment is carried out of the new location of care. Clear lines of communication should be agreed and the family should be provided with information about how to access 24 hour help.

Investigations should continue to be planned which will guide ongoing management of the baby after leaving hospital. This may include planning for postnatal reviews by other specialist teams such as neurologists or cardiologists.

Ambulance transfer

- Ambulance transfer may not be needed, but if it is, the transfer should be undertaken when the baby is as 'stable' as possible. For example, if the baby is intubated and ventilated, it is unlikely to be in his or her interests to be extubated prior to the move. Planned withdrawal of other

treatments should be stopped only on arrival at the destination if they are likely to impact the stability of the infant in transit.

- In addition to an Advance Care Plan (ACP) (see page 32), there should be clearly documented plans for actions to be undertaken in the event of cardiopulmonary arrest whilst in transit. Ambulance staff must be aware of this plan and agree to follow it prior to leaving.
- Families may agree that the ambulance should continue to the destination whatever happens en route or may agree that in certain circumstances the ambulance should divert to the nearest Emergency Department. In other situations, families may prefer to return to the referring unit and to a team that is familiar to them.
- Parents must be involved in all decision making and fully understand the possible outcomes of the transfer.
- Consideration should be given to the availability of medical staff (at the preferred destination) to complete a death certificate and cremation forms (where appropriate).
- All neonatal units will have access to dedicated neonatal transport services through their networks. Whilst some neonatal intensive care units will have a transport vehicle of their own, others may have an arrangement with local

ambulance services. If this is required, referrals to local ambulance or transport services should be made as early as possible, to minimise delay.

- Developing a relationship and agreed transport protocol with the local ambulance service can be very helpful.

Transfer in the family's own transport

- Families may choose to use their own vehicle to take their baby home and they may wish to choose another family member to drive. If the infant dies in the family's own transport, they may choose to return to the referring unit (for example, if they have not yet met a hospice or community team), or to continue to their destination. Families should be asked to consider what their choice would be in this situation before setting off, so that the teams can be alerted.
- If the family wish to continue to home, their GP (or an appropriately trained nurse) should be contacted prior to discharge to warn them of the potential need to confirm death.

- The arrangements made prior to discharge for the completion of death certificates/cremation forms should be documented and agreed.

Transfer in hospice transport

- If the family is using hospice transport and there is a death in transit, it is likely that the baby would be transported to the planned destination, but a clear plan should be agreed with families prior to departure.
- The children's hospice should be notified of the death in transit as soon as possible – as some of these families will already have been receiving support from the hospice in the antenatal period and the hospice staff will be key in assisting and supporting the family and the neonatal team at this time.

Bristol Children's Hospital has an ambulance service (WATCH) which will transfer a ventilated baby to the family's local hospice or to home for extubation. There are similar ambulance teams throughout the country that offer this service.

Case study 2:

Teagan's story, shared by Mum Hazel

It came as such a shock to us when Teagan was diagnosed with a life-limiting condition at five days old – she lived for 23 days, but I would not have wanted her care or our care to be any different. We wanted our time with her to be as 'normal' as possible.

We were quickly offered the opportunity to take her home and once this happened it allowed us to spend quality time with Teagan and her big brother. It also enabled family and friends to visit us with their own children. We had a family Christmas and even managed a visit to a pre-arranged family photographer session where Teagan managed to stay awake throughout.

This time at home was made possible by the nurse, GP and paediatrician's support – they offered a range of help – for example, with Teagan's nasogastric feeds and medication for her secretions. They provided advice about our financial arrangements whilst my husband had to be off work and preparation for what would happen when Teagan deteriorated at the end of her life.

Teagan died at home at 8pm on Friday 27 December – using the information we had in our care plan we made the phone calls we needed to and then she stayed with

us in our room overnight.

Due to the time of year her funeral was several days later. We decided to keep her at home long enough for close family to say their goodbyes, then the funeral director collected her in a beautiful moses basket.

Since our time with Teagan, several families have been offered similar support and had their babies at home at the end of their lives – we didn't realise we had been the first in the area! In the months following Teagan's death we raised money to provide a cooling mattress which is now available in the community if families wish to keep their babies at home for longer after they have died.





A full assessment
will ensure the right
professionals are involved
early on and in a
co-ordinated way.





Stage two: Ongoing care

To help families access the full range of care and support for their individual situation there will need to be a full assessment of the baby's and family's needs. This assessment process should begin as soon as possible after diagnosis and should be multi-agency, involving assessments of health, psychosocial and practical needs.

Antenatally and immediately post-birth there may not be many different agencies involved with the family, but a full assessment will ensure the right professionals are involved early on and in a co-ordinated way. This is a time of continuing uncertainty and many parents feel overwhelmed with the many decisions and choices they are asked to make and will need ongoing opportunities to discuss things. Planning for this ongoing care is an important part of parallel planning for the family, ensuring that options are explored fully.

The third standard: A multi-agency assessment of the family's needs

Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.

Goals in a multi-agency assessment of the family's needs

1. Babies and families should have their needs assessed as soon as possible after diagnosis or recognition.
2. A holistic and collaborative approach should be used to avoid the need for multiple assessments.
3. An assessment of needs should be made in partnership with the family.
4. The baby should be kept central to the process – it is important to acknowledge that the family is part of the team caring for their baby.
5. Family-centred care should be practised, considering the needs of the whole family.
6. The family's religious, spiritual, cultural and personal beliefs should be respected.
7. Straightforward and jargon-free language should be used and written information should be used where possible.
8. Assessment information that is gathered should always be available to the family.
9. It should be clear who is taking the lead role.
10. Those undertaking assessments should have appropriate skills and local knowledge.

What this means in practice

Where possible, planning should be multi-agency to bring together all the services that may be required to provide support to the family while they are in hospital, if they go home or go to a setting such as a children's hospice. The assessment should be for the baby, parents and wider family, including siblings.

It's acknowledged that in reality the fast-paced neonatal environment doesn't always enable this degree of multi-agency planning to take place, however it is important to bring together different professionals to form a multi-disciplinary team (MDT) – to plan and implement treatment for the baby and support for the family, and to bring in other agencies whenever possible. One service or agency should take a lead to co-ordinate joint working and ensure families are enabled to take control of their situation and helped to access the various services, equipment and support they need (Kuhlen, 2016).

It will be important to explain to the family at an early stage about multi-agency or MDT working. They will want to know who will form the team around them and how they will be involved in their care. It is also important to highlight how different members of the team may be involved if there are changes to the care being provided or to the care setting. The family should be acknowledged as being part of the team and attend MDT meetings where possible.

Where possible, a multi-agency needs assessment should be carried out by staff with appropriate competence and local knowledge. It should be seen as an ongoing process rather than a single event. The aim of the assessment is to examine all the individual factors that impact on the baby and family's quality of life and guide the delivery of specific services to meet their needs. Information should be recorded systematically and stored securely.

For those families who are planning to go home, the appropriate level of medical cover in the community will be an important consideration. For many families, the management of the baby's symptoms will be the prime consideration. They need to feel assured that their baby will be as pain and symptom free as possible and know who to contact for help with this on a 24 hour basis.

There will need to be an assessment of what other services are available in the community and plans put in place to enable good co-ordination of care. Local community children's nursing (CCN) teams, community neonatal services, child development teams, and in some areas children's hospice neonatal link nurses, could all play a role in supporting the family at home.

There may be a children's palliative care team available to support the family and this service could provide a range of specialised support for families in this situation, including:

- doctors with expertise in children's palliative care, sometimes at consultant level
- nurses with expertise in paediatric palliative care
- pharmacists with expertise in children's palliative care
- experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support).

Equipment needs should also be assessed and any support related to financial matters.



The fourth standard: Co-ordinated multi-agency care plans

Every family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. If the plan contains separate documents they should be clearly linked up and shared. A key point of contact should be identified and agreed with the family.

Goals for a co-ordinated multi-agency care plan

1. A multi-agency care plan should be agreed and recorded for the current and future care of every baby with a life-limiting condition and their family.
2. The care plan should be made in partnership with the family.
3. The care plan may cover planning for antenatal care, birth, postnatal care and the broader health and social care input to the family; if they are separate documents they should be clearly linked up.
4. As part of care planning a key point of contact should be identified and agreed with the family.
5. The care plan should include up-to-date contact information for key professionals involved in care, agreed treatment plans and objectives and an agreed approach to communicating with and providing information to the parents or carers.
6. Care plans should be regularly reviewed and families should be able to request a review at any time.

What this means in practice

Following the needs assessment process described in the previous standard, a multi-agency care plan can be drawn up to set out the agreed level of support the family requires and the services that should be involved. The multi-agency care plan should be one document or a series of working documents that are linked and shared, providing details of all the professionals and services required for the specific needs identified in the assessment process.



The priority is to ensure the family has access to the required co-ordinated services and range of professionals. Families will need reassurance that everyone they come into contact with will understand their needs. A consistent, open and honest approach will help them to build trust with different professionals.

Some families may have minimal needs from services in the early stages, but their needs may change over time and additional agencies and services will need to be involved. The care plan therefore needs to be responsive to these changing needs and/or changes in the baby's prognosis and will need to be reviewed regularly. Having a documented care plan should mean that families don't have to repeat their needs over and over again.

For most families, the multi-agency care plan will include an Advance Care Plan (ACP) (which will include, for example, the family's wishes for the baby's end of life care, decisions about resuscitation and care of the baby's body after death), a symptom management plan, and an emergency care plan (sometimes including an escalation plan). Sometimes the speed of responding to a baby's changing needs will dictate what can be agreed and what is appropriate to include at that point in time.

Depending on the stage of care at which the plan is made, it may cover antenatal care, birth, postnatal care and the full range of health and social care that is to be provided to the family at home. A parallel planning approach (as described on page 17) should be taken so that plans are made with the family for both the baby's ongoing care and their end of life care.

Advance Care Plans (ACP)

An Advance Care Plan is a formal care plan that includes details about the baby's condition and the decisions, wishes and ambitions of the baby's family including discussions and decisions that may have taken place on organ and tissue donation.

This plan should be developed at an appropriate time, setting out both current and future needs of the baby and wishes of the family. The ACP may contain different elements such as an end of life care plan, which is described more fully in the end of life care planning section on page 35.

Antenatally, parents should be offered a discussion with a consultant neonatologist and ideally the palliative care team as soon as the diagnosis is confirmed and certainly by the time the baby has reached viability. This can enable relevant information about the life expectancy and quality of the baby's life to be discussed and an informed decision to be made about whether to continue with the pregnancy or not. Both the option of termination of pregnancy and continuation of pregnancy with parallel palliative care planning should be presented to parents and fully discussed. Sharing this news with the family requires great skill and sensitivity.

A palliative care plan may be part of a woman's care at any stage of her pregnancy. Antenatal discussions and postnatal care planning should be documented in an antenatal ACP for the baby and filed in the maternal hand-held notes with a copy kept in the hospital delivery suite and the neonatal unit and shared with the GP and community midwife team. It will need to be shared with the maternity MDT if the pregnancy is over 24 weeks. For multiple birth pregnancies, this plan should take into account the needs of the baby with the life-limiting condition and their unaffected sibling(s).

It is helpful to share the family's wishes in advance so that the midwife or obstetrician can have early discussions with them about any risks associated with the choices they have made (for example if a woman wishes to have no electronic fetal monitoring in labour, advance knowledge by the midwife or obstetrician will allow early discussions of risk and choice and will minimise the risk of conflict).

Antenatal Advanced Care Plan

At the initial discussion, where appropriate, a Consultant in Obstetrics and Fetal Medicine, Neonatology and Children's Palliative Care should confirm and document the information on diagnosis and prognosis of a baby's condition including the need for palliative care starting in the antenatal period. Multi-disciplinary discussion and the input of a second consultant should ideally be part of this decision-making process if the diagnosis/prognosis is not certain.

This antenatal anticipatory ACP should include:

- details of diagnosis, options offered regarding place, timing, mode of delivery and monitoring in labour
- input from a fetal medicine consultant if there are discussions about continuing the pregnancy
- where the baby should be delivered and whether specialist facilities will be needed
- people to be present at delivery and the care to be provided at delivery
- a record of any discussions and decisions that have taken place on the extent of resuscitation
- a record of any discussions and decisions that have taken place on organ and tissue donation
- details of postnatal care for the baby, including parents' wishes relating to skin to skin contact and their preferences for how other people can come and see the baby

Symptom management plan

Symptom management care planning aims to support both the family and professionals to provide optimal care for babies. A doctor experienced in palliative care and in the management of babies' symptoms should be involved in the development of the symptom management plan. It should set out the potential symptoms a baby may experience and their cause, recognising that often a baby's discomfort may be caused by a combination of factors which will require an individualised management approach.

The plan should include the starting dose of medications and potential for escalation of doses. This can be very helpful to the family GP or community nurses who may be involved in delivering end of life care if the baby is at home. This planning should take in to account whether routine interventions are necessary or essential to the baby's care.

As well as pharmacological approaches, the plan should also set out the non-pharmacological interventions that may help the baby to relax (Mancini et al 2014), for example:

- environmental adjustments (for example, reducing noise)
- music
- physical contact such as touch, holding, massage and skin to skin care
- comfort measures, such as sucrose for neonates
- comfort triangles – mothers provided with knitted material that can be swapped between herself and her baby so that both get comfort and the baby recognises the mother's smell

Escalation planning

If the baby is being cared for at home, the family will need to have a clear escalation plan which covers what will happen out-of-hours and who to contact should they need support. This may vary and include an on-call community children's nurse or other care professionals such as the family GP. It can be helpful to inform parents that if their baby requires re-admission to hospital, this is likely to be to a children's ward and not the neonatal unit where their baby was originally cared for. The re-admission may be to a different hospital.

Reviewing plans

The baby's and family's needs should be reviewed regularly and the family should be able to request a review at any time. Families should be given extra support at key times, particularly following a change in the baby's condition, or a family crisis. A new care plan should be agreed to reflect any changes.

Case study 3: Jack's story, shared by Mum Mary

Jack was born premature and suffered severe brain damage as a result.

We were daunted by the fact we were referred to the hospice, worrying it was for end of life care. Also, we could not get over how the transition from hospital to the hospice and then home was possible in a week.

Within the first day staff reassured us that we could learn to manage Jack's ways and allow him to enjoy life.

The whole environment was happy and relaxed, which relaxed us and Jack. It was so much nicer to bond with Jack and be a 'normal' mum in a non-medical environment.

Jack's doctor at his children's hospice said "since those early days, Jack has faced challenges with severe reflux and occasional chest infections. He

has remained a regular respite visitor and we have enjoyed supporting him along on his journey. In the last year he has undergone gastrostomy surgery and has shown real progress in his skills. His delightful personality and strength of character, combined with his parents devoted efforts have contributed to him becoming a delightful boy with a much more positive outlook than was anticipated in those difficult, uncertain early days."



Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.





Stage three: End of life and bereavement care

Predicting the time when a baby is likely to move into the final phase of their life is not always easy. The realisation that death is imminent may only be days or hours before it happens. The family may have little time to process the information or plan for the death of their baby.

For others, transition into the end of life phase is clearer, especially in cases where there has been a decision to stop all life-prolonging treatment. The baby's quality of life and comfort up to the point of death will be a major consideration, and there may be difficult decisions surrounding the withdrawal of non-essential drugs or other invasive interventions.

The fifth standard: An end of life care plan

Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.

Goals in planning for end of life care

1. Professionals should be open and honest with families when it is recognised that the baby is approaching end of life.
2. Joint planning with families and professionals should take place as soon as possible.
3. A written plan of care (ACP) for the baby and family should be agreed, and reviewed to take account of any changes, including decisions about methods of resuscitation.
4. End of life plans should be reviewed with the MDT, GP or doctor at least every two weeks.
5. There should be 24 hour access to pain and symptom control including access to medication by suitably qualified and experienced professionals.
6. Supplies of medication and equipment, and out-of-hours pharmacy and equipment needs should be discussed, planned and documented in a symptom management plan. This may need to happen urgently if the baby's health is deteriorating rapidly.
7. Families should be given emotional and spiritual support, including siblings and grandparents before the baby dies, at the time of death and immediately afterwards as part of the end of life plan.
8. Fully informed consent should be sought for post-mortem examination and the findings fed back by an informed professional that the family know in a face-to-face setting.
9. Professional contacts should be informed of the baby's death immediately.
10. Staff involved should have access to their own lines of training, support and supervision.

What this means in practice

This is a very difficult time for the family and it may be the point when they face up to the reality of their baby's death for the first time. Professionals working with the family should be open and honest about the probability that their baby's life is nearing an end. It will be important to discuss with families that the course of their baby's condition may be unpredictable, and that their baby may die sooner or later than expected. Every family should be helped to prepare an end of life plan and should be provided with care and support to achieve this by a small core team.

The end of life plan should include details of how to achieve death in the location of choice, where possible, symptom management, and resuscitation. It is important to clarify who will be providing nursing and medical support and to ensure they have appropriate skills and knowledge in providing end of life care, particularly in symptom management and prescribing for babies in this situation.

Professionals sometimes find it difficult to 'let go' of the baby or family and may themselves need support to recognise that families need privacy and precious time alone with their baby. It is good practice to have a pre-death and a post-death MDT meeting to help staff explore some of their feelings and make sure robust plans are in place.

Planning for end of life

End of life is difficult to predict in all babies with complex needs. Teams may need to be available to sustain days or weeks of care at end of life, and have contingencies for support if a baby's end of life phase is prolonged. Care plans need to be devised that are sustainable and not dependent on the goodwill of one or two practitioners. As part of this parallel planning, there should be a regular review process in place ensuring families are effectively followed up. Appropriately staffed and trained teams are essential to provide the quality of care required (NICE, 2016).

Planning care for an emergency should have been documented. This is helpful for families caring for a baby at home as staff will need to be updated on each visit about changing plans. This plan should be shared with all professionals to be involved, including ambulance crews and local accident and emergency departments. Most local ambulance services offer the facility to provide this key information when an ambulance is called to a 'flagged address'. This is especially important if an 'out-of-hours' service is involved.

Parents may choose and it may be appropriate for them to care for their baby at home for their final few hours or days. It is important that the family and the team have 24 hour access to a children's palliative care specialist, paediatrician, nurse or specially trained GP so that pain and symptoms can be managed, and emergency admissions to hospital can be avoided.

The suggestion may be made that the baby should not be resuscitated. The precise details of this should be fully explored with the family and documented in the ACP. 'Do not resuscitate' discussions are a very important part of the anticipatory planning process to reflect appropriate interventions for the baby. If there is not a 'do not resuscitate' order in place, the default position is to attempt to resuscitate the baby (NICE, 2016), so it's important that these discussions take place as soon as possible.

Symptom management at end of life

The baby should receive effective pain and symptom management and regular symptom reviews should take place, as per the symptom management plan (see page 32).

Appropriate pain relief should be administered at regular intervals with other associated drug therapy for symptom and side-effect control. There may be other distressing symptoms such as agonal respiration (gasping respiration) and the family will need reassurance that although frightening to watch, these can be managed effectively so that the baby is not distressed (see Appendix 2).

Some neonatal units will use 'grab bags/boxes' which contain commonly used drugs at end of life. Clear labelling of the drugs and the prescription chart to be used outside the hospital setting should be clarified before discharge. Plans need to be made for returning or destroying any unused medicines.

Place of death

Families should be supported to discuss where they wish their baby to die and this conversation should be in an environment in which the family feels most comfortable. As described in Standard 2 on page 24, many families will be in hospital and choose to stay there, some may wish to be at home and others may choose a children's hospice. With efficient co-ordination from the medical lead and key point of contact and collaborative working across the appropriate services, a combination of these places

is also possible. It is important to only offer what is deliverable in your location, so if a home death cannot be supported by a service it should not be offered. However, it may still be possible to take the baby home or to a children's hospice after they have died. Some babies may be ventilated and the family may wish for them to be extubated at the local hospice or at home. This will need careful planning, with a parallel plan in place following extubation (ACT, 2011). Whatever the choice, the family will need 24 hour telephone access to support them at their baby's end of life.

As described in Standard 2 of this pathway, rapid transfer arrangements will need to be made to allow urgent transfer to the preferred place of care. If it is suspected that a baby may die soon and they are not in their preferred place of death, it should be discussed with parents whether a rapid transfer is realistic and in their baby's best interest.

When planning rapid transfer to the preferred place of death, review any intended changes to care and when they should happen including:

- care for the final hours or days of life
- planning for if the baby lives longer than expected including planning for at least 24 hours support at home
- support for the family after the baby dies
- care of the baby's body after death
- which professionals will be involved and what their responsibilities are
- who will help with the practical and administrative arrangements after the death (for example, completion of the medical certificate of cause of death)

Conflict

Occasionally there may be conflict between the family and professionals about the best interests of the baby and it can be useful to seek an ethics review by the local clinical ethics committee to resolve these issues. The Royal College of Paediatrics and Child Health has published guidance about making decisions to limit treatment in children with life-limiting and life-threatening conditions (Larcher et al, 2015). There is also practical guidance for the management of palliative care on neonatal units, published by Chelsea and Westminster Neonatal Team (Mancini et al, 2014) which provides supportive information about difficult decision-making.

Extubation at end of life

When a decision has been reached between parents and the neonatal MDT that intensive care is not in the best interests of their baby, the end of life process may need to involve removal of the endotracheal tube – this is called extubation at the end of life or sometimes termed 'compassionate extubation'. Discussion must commence about when, how and where to carry this out.

Extubation is an event often dreaded by families as they do not know what to expect. It requires collaboration between neonatal staff and the family. If time allows, a well-constructed plan that is carried out in accordance with the family's wishes, including recording any discussions on organ and tissue donation, can provide a truly valuable and meaningful final time for a family to be together with their baby (ACT, 2011).

The family should be counselled as to what is likely to occur once the endotracheal tube is removed and the physical changes that are likely to occur as their baby dies. Parents should be made aware that the time until their baby's death can vary from minutes to hours, and sometimes days or longer in some instances. It will be important to have had a conversation with the family that once the baby has been extubated it may not be possible or in the best interest of the baby to be reintubated.

Parents can also consider whether to have the extubation carried out outside of the hospital, for example in their own home or in a children's hospice if this is a realistic and safe option. For this to happen, rapid transfer arrangements must be in place between the local services, as described on page 25. Not all babies will be stable enough to survive the transfer out of the hospital and if this is the case it should not be offered.

Supporting families to make memories

For many families, memory-making is important when life is short and the future uncertain. Many parents and some professionals may not know what is possible and will need support to make memories and keepsakes both before and after the baby has died. They will need to be supported early with this, at the start of the care planning process. Families may wish to make memory keepsakes such as remembrance photography (both before and after the baby has died), hand and footprints, or keep a lock of their baby's hair. They may wish to include siblings in this, for example, integrating all their hand or foot prints into a picture for the siblings to have as they grow older. For multiple birth families,

it is important to ask them if they want photos and keepsakes for both the baby by itself and as part of its multiple birth sibling group.

If the family have not already done so, they may want to arrange a Christening or other ceremony to name their baby. A Christening is normally done by a Church minister but in an emergency, can be done by anyone who themselves has been baptised.

Supporting families to be involved in care at end of life

Parents and other significant family members should be encouraged and supported to continue their caring role with the baby during their death. If the parents wish, siblings, grandparents and other family members, where appropriate, should be included in this. Parents should be consulted about whether they want to be involved in caring for their baby after death, helping with washing them and choosing their clothes.

Emotional support for the family

This will be an extremely painful time for the family. Professionals should be sensitive to the family's individual coping and grieving processes and their need for privacy, space and support. Emotional support is essential at this time and the wider family's emotional needs should also be supported. Grandparents in particular may need sensitive consideration as they are likely to be grieving not only for their grandchild but also for their own child's sake.

Siblings should be given opportunities to express their emotions openly and ask questions, as their needs can often be overlooked by busy professionals, or by parents overcome with grief. Parents should be encouraged to ask their children if they wish to see their brother's or sister's body and to include them in decisions about funeral arrangements, giving them age-appropriate information to help them to prepare for this.

Siblings may wish to make a special contribution such as a prayer or a poem, or they may wish to place a gift or memento into their brother or sister's coffin. This will need to be checked with individual funeral directors as certain items are not allowed in coffins, but it should always be possible for such items to stay in the coffin until the funeral, after which they can be returned to the family.

Practical help for families

Families may also need practical help with finances or returning to work and may need signposting to information about this. Parents will need information about what they need to do after their baby has died, and this is also a helpful time to listen to any concerns they may have.

The family will need written information about procedures and entitlements following the death which should include:

- registering the death (and, at times, the birth)
- procedures required for cremation
- contact details for funeral directors
- contact details for local religious leaders
- advice on benefits or other entitlements
- contact details for care staff

It should be remembered that the mother is likely to still have health needs following the birth and may need midwifery input. She may wish to talk to her midwife about donating breast milk to a milk bank.

Care of the baby after death

Families need to have time and privacy with their baby in the hours and days following the death. They may want to retain control and choice in the care of their baby's body and should be supported to do this. They need to know that they have choices and that whenever possible their decisions will be honoured. Planning ahead for the care of the baby's body before the baby dies will enable any equipment to be provided in advance, for example to enable the family to bathe their baby after he or she has died. In many neonatal units and children's hospices there are facilities to allow the baby's body to be cared for in a cooled room or in a cool cot.

Some families may decide they wish to transfer to another setting, such as a children's hospice or home, and this should be supported wherever possible. This transfer request should be recorded in the baby's notes. It will be necessary to inform the mortuary and bereavement team to enable them to record this information and support the family. It is also good practice to inform the family GP and any other professionals who may visit the family home.

If the family wish to take their baby home after the baby has died, they should be given the details of a key contact to support them there. This could be the neonatal community team, community midwife, health visitor or funeral director. It is

possible to arrange a mobile cooling device in the family home, usually from the maternity or neonatal unit, or sometimes via the local children's hospital or hospice service.

Families may have rituals and ceremonies important to their faith that they would like to be observed at the time of their baby's death or immediately afterwards. They may need to discuss their beliefs and values more than once with the team to help them to decide what they would like to do (Nash et al, 2015).

Mortuary teams

Some parents have great anxiety over their baby being transferred and left alone in the mortuary. It can be helpful to arrange for the family to meet mortuary staff and ask them questions that can help them to make choices following the death of their baby. The mortuary staff are specifically trained in caring for babies after death and they may have information which the parents find useful.

Mortuary staff may be able to help in reducing the time parents will be separated from their baby if that is an important factor for them. Some parents will say goodbye and not want to see their baby again until their chosen funeral director has collected and prepared their baby for cremation or burial.

Some parents may want to visit the place their baby will be cared for after death and this is usually facilitated by the mortuary anatomical pathology technologist (APT) or nursing staff.

If the baby is being cared for in hospital, parents may not want to come to the mortuary but may still wish to meet the staff who will care for their baby after death. This can usually be arranged so the APTs can visit on the neonatal unit, answer any questions the parents may have and meet the baby if that's what the parents want. It is important to understand what is available locally as this will differ from one hospital to the next.

Examination after death – post-mortem examination options

When a death is expected, it is usually not compulsory for a post-mortem examination to take place, (see page 40 where we talk about the coroner) however there may be circumstances where the family will find it helpful to be offered this choice. They may want to understand the implications for future pregnancies or want to contribute to further understanding of their baby's condition.

Parents should be fully informed about the different post-mortem options, which include less invasive options such as imaging or tissue biopsy, and be provided sensitively with written information about these options. Consent should be obtained from parents by staff who are trained to do this, so that they are reassured that nothing will be happening that they have not agreed to. Parents should feel that their decisions are understood and respected by all concerned and know they are free to change their minds about what they are choosing at any time. It is important to ensure their decisions are recorded to prevent the same questions being asked repeatedly.

It is important to understand what can happen locally as this will differ from one hospital to the next and may involve the baby being moved by professionals to another location for a post-mortem examination. Regardless of where the baby dies, a post mortem examination can still be arranged if parents choose this and it is something that parents can discuss with the mortuary staff or bereavement team.

Verification and certification of death

Verification of death is the procedure of determining whether a baby has actually died and is the physiological assessment to confirm the fact of death. Certification of death describes the legal process of completing the medical certificate of cause of death and is the essential preliminary to registration of death. This process must be carried out by a medical practitioner.

Verification of an expected death can be carried out by nurses if they are competent and have received appropriate training (Together for Short Lives, 2012).

Many families worry about what they 'have to do' when their baby dies. There are only two legal requirements to fulfil:

1. Obtaining the death certificate – the death certificate will be signed by a doctor wherever the baby dies. Deaths of babies aged up to 28 days must be recorded on a different certificate from those over 28 days. (This is not the case in Scotland where all deaths are certified on a common certificate.)
2. Registering the death – the baby's death must be registered within five days (eight days in Scotland) and the family will then receive the documents they need to organise their baby's funeral. If the coroner has been informed in advance, the time scale does not apply.

All professionals should be aware of the law and policies to be followed in their local area and help ensure that agreed procedures are followed.

Referral to the coroner

If death is unexpected (for example, a sudden death after surgery) or suspicious in any way, this must be reported to the coroner as a post-mortem may be required. It is advisable to notify a doctor and coroner (procurator fiscal in Scotland) simultaneously. If the coroner requests a post-mortem the family will not be able to refuse the examination taking place and will need to be given full and sensitive information about the process.

Notifying other people of the death

Immediately after the baby's death, it is important to inform all professionals in contact with the family. Professionals in the care team can assist in this if the family wishes.

Other relevant organisations should be notified of the baby's death, such as the local Child Death Overview Panel (in England and Wales), which reviews the deaths of all local babies and children. In the case of babies who die in a children's hospice, the registration body should also be notified (in England, this is the Care Quality Commission).

It is also important to inform any department or service expecting the baby at an appointment to ensure that 'did not attend' letters are not sent out.

Where appropriate, the Child Benefit Office should also be informed as parents are entitled to up to eight weeks of child benefit if they claim within three months of the baby's death. The baby's parents will still qualify for maternity and paternity pay.

People to contact may include:

- neonatal services
- midwife
- GP
- community or specialist nurses
- health visitor
- social worker
- children's hospice
- religious leaders
- sibling's schools
- ambulance service
- specialist donation services team
- mortuary service

Organ and tissue donation

Organ and tissue donation can be considered for babies who are at term or near-term. These considerations may affect the families' choices of planned place of death for their baby. Discussions should take place at the earliest opportunity with the Specialist Donation Services Team who will guide the process and work alongside families and the neonatal teams to ensure that only realistic options for organ and tissue donation are offered as part of end of life care planning. A referral to this team can be made at any time once end of life planning has begun.

Organ donation is only possible following a withdrawal of life-sustaining treatment, or determination of neurological death, usually within a hospital environment (Larcher et al, 2015). It may also be possible immediately after a planned delivery of a baby, where an antenatal diagnosis has been made of a condition that is likely to result in imminent death, and where pre-planning has occurred to facilitate the donation process.

Tissue such as heart valves can be transplanted to enhance and sometimes save the lives of people, including very young children. This can be seen by a family as a positive event following their baby's death and therefore can be discussed with them if their baby meets the criteria for donation. Families and the teams caring for them can request to discuss this with the National Referral Centre on 0800 4320559 (see Appendix 5).

Funeral planning

Families should be made aware that they can choose whether or not to have a ceremony, and that they can have more than one if they wish. They could reflect upon what they hope a ceremony will achieve. It may provide:

- a chance to bring together everyone whose life was touched by their baby, to say goodbye and draw comfort from each other
- an occasion to hold as a memory that they can look back on
- an opportunity to share the joy that their baby brought to their lives and to the lives of others
- a religious ritual
- a quiet 'parent only' time



Sometimes families may want to talk about their baby at the funeral, but feel they are unable to do so. If this is the case, they may want to consider making a recording that could be played at the funeral. They may also find it useful to talk to someone who has previously arranged such a service for a baby.

Staff support

Professionals sometimes find it difficult to 'let go' of the baby and family and may themselves need support. Following the baby's death staff may find it helpful to use a range of support methods such as debriefs or reflective practice. This can help to reduce their levels of stress, risk of burnout, compassion fatigue and increase their job satisfaction.

It can be helpful to provide psychological support for staff providing palliative care on neonatal units (Mancini et al, 2014). It may be possible to access this form of support from a children's palliative care team.

The sixth standard: Continuing bereavement support and care

Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond.

Goals in continuing bereavement support and care

1. Parents should feel in control of events before and after death and should be able to follow their own choices and wishes.
2. Bereavement support should be offered based on assessed needs and take into account local and national sources of support.
3. Where needed, professional bereavement support should be offered by someone with appropriate expertise.
4. The bereavement needs of siblings should be recognised and supported.
5. Parents may want details of who they can contact to discuss any plans for a future pregnancy or to be put in touch with a genetic counselling service.
6. All families should be offered a follow-up appointment with their consultant and/or care team so that they have an opportunity to reflect and ask questions about the quality of care they and their baby received.
7. The needs of care staff should be considered including supporting those staff who are ending their involvement with the family as part of an agreed bereavement plan.

What this means in practice

The death of the baby is not the end of the pathway for the family. They will be grieving for many months and years to come. The family's bereavement support needs should be assessed and planned by their key contact, ensuring that families are signposted to appropriate services.

When planning bereavement support for parents or carers, talk to them about the support that is available and explore with them what they would find helpful and acceptable.

It is important to recognise that grief and bereavement are natural processes, however specialist bereavement support should be offered to all parents who have experienced the death of a baby. Some people will find their way through its complexity without needing this support but families may need a menu of services to be offered at different times (Wimpenny and Costello, 2012).

The family should know what help is available and feel able to ask for help if they need it. Those in the team who are working with the family should make follow-up contact based on assessed need and, if needed, liaise with the lead bereavement professional to ensure that the family's needs are met. Bereavement support may be provided through referral to the family GP or a local children's hospice.

Some families may find it helpful to set aside an identified time each day within the first few months when they know they can focus on the death of their baby, rather than feeling that their grief consumes them every hour of the day. It can be helpful if difficult times such as birthdays, religious festivals, or the anniversary of the baby's death are remembered and marked by the care team.

Particular care is needed with siblings. Brothers and sisters have been referred to as the 'forgotten mourners' because they may not have expressed their needs directly (Hindmarsh, 2000). Siblings are affected not only by the loss of their brother or sister, but by the impact this has on the family and the relationships within it. Children should be included and not be shielded from the grief felt by others in the family, so that they do not feel that they have to hide their feelings. They can experience being protected from the truth as exclusion.

The family may also experience secondary losses such as the changed nature of their relationships with one another, with other family members or with the professionals who have cared for them and their baby. The intensive involvement, the feeling of friendship and support of members of the team will largely cease and many families feel suddenly cut off from what was previously a major part of their lives. In addition, they may suffer financial hardship as allowances are likely to be withdrawn or reduced. The family GP and primary care team should provide as much support as possible and should be prepared to provide support for many years.

Where parents lose a twin or triplet there can be complex emotions around feeling the joy of having a well baby at the same time as dealing with loss. Most parents value being given 'permission' to grieve for their loss, while celebrating their surviving baby. It is essential to recognise that the pain parents experience at the death of their baby is not reduced because they have a surviving sibling. If parents wish, staff can help them to recognise and mark the fact that the surviving baby was one of twins or triplets, for example by marking the cot with a purple butterfly.

In 2017 a National Bereavement Care Pathway was developed by Sands, the Stillbirth and Neonatal Death Society, who worked in collaboration with other charities and with the support of the Department of Health and the All Party Parliamentary Group on Baby Loss. This is available online: www.nbcpathway.org.uk/pathways/.



The NICE guideline describes the care and support that babies with life-limiting conditions – and their families – should expect to receive.





Appendices

Appendix one: The role of the National Institute for Health and Care Excellence (NICE)

Guidance on end of life care for infants, children and young people with life- limiting conditions

This guideline, published in December 2016, describes the care and support that babies, children and young people with life-limiting conditions – and their families – should expect to receive from the point at which their needs are recognised until the end of their lives. Quality standards have been produced to support these NICE Guidelines [QS 160] in September 2017.

NICE recommends:

- Where possible, the baby receiving palliative care, including end of life care, in the place they choose.
- Babies with life-limiting conditions should be cared for by a multidisciplinary team who meet regularly to discuss the child's care.
- Parallel planning, so that families and professionals are prepared for a change in the child's condition.
- Involving neonatal medical teams in care planning for a child if there is an antenatal diagnosis of a life-limiting condition.
- Recognising the importance of managed clinical networks in delivering high-quality coordinated children's palliative care.
- The baby's family should play an active role in discussions about their care.

The NICE guideline is a vital tool for professionals delivering perinatal palliative care and for commissioners who plan services. It provides a clear direction for commissioners and providers to work together to plan, fund and deliver high quality palliative care for babies and children so that all babies and their families in the UK can access the best care.

Organisations commissioning and delivering services are expected to take the recommendations contained within NICE clinical guidelines into account when planning and delivering services.

Appendix two: Research in perinatal palliative care

In the ten years since the publication of the original pathway in 2009, there have been significant developments in the field of perinatal palliative care and a useful body of research has begun to shape practice. Over the last decade, perinatal palliative care has developed into a recognised, holistic discipline in its own right. Rather than considering only the decision making around babies unhelpfully (and often inaccurately) labelled as having 'lethal' diagnoses; it now extends to consider their needs over a potentially longer lifetime as well as those of their families (Vesely, 2013; Wool, 2013).

Studies suggest that increasing numbers of women (and their partners) are opting to continue with pregnancies after the diagnosis of a severe fetal abnormality (Madeuf, 2016). Not only do families report positively on the experience of

continuing such pregnancies (Cote-Aresenault, 2016) but a number of the infants go on to survive, demonstrating a degree of diagnostic or prognostic uncertainty in antenatal counselling.

Significant difficulty remains in the interpretation of symptoms in very immature infants. Their responses to pain are qualitatively and quantitatively different (Fitzgerald, 2009) and the significance of 'gaspings' remains much debated (Durrmeyer, 2016). Whilst some authors discuss the use of opioids in the delivery room (Garbi, 2016) and increased use of benzodiazepines following the introduction of active palliative care programmes (Younge et al, 2015); little consensus exists to guide practice. The Association for Paediatric Palliative Medicine (APPM) Formulary offers some guidance based on the limited evidence available.

Fortunately, the social and cultural importance of being able to feed a baby is now better understood (Chichester and Wool, 2015), and the benefits of complementary and alternative approaches to holistic supportive care are beginning to be appreciated (Wool, 2015).

The practice of organ and tissue donation from neonates has also advanced rapidly in recent years, and it may now be considered ethical to electively ventilate a baby with the intention of facilitating organ donation, following a diagnosis of conditions such as anencephaly (Jivraj et al, 2016; Larcher et al, 2015).

Efforts have also been made to understand the needs of staff from various backgrounds, who may be asked to deliver perinatal palliative care. A recent study of midwifery staff caring for babies who died in the delivery room, highlighted that staff were comfortable delivering medical care to the infant but may be distressed by having to support grieving parents (Garten, 2015). Such distress may be minimised by offering training in communication or counselling skills as well as adequate staff support. On-line training modules are starting to be offered by the Royal College of Midwives and the International Children's Palliative Care Network (ICPCN).

Proposed models have been published, by teams in a wide range of different clinical settings (Sidgewick, 2016; Denney-Koelsch, 2016; Kenner, 2015). The common themes of co-ordinated, family centred care supported by clear communication are reflected throughout this pathway.

Some services have gone on to start early work examining possible quality standards for

perinatal palliative care (Wool, 2016; Gilmour, 2016). NICE will produce quality standards for end of life care for infants, children and young people in 2017 to accompany the guidelines published in 2016. NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care.

The views of families are the ultimate metric of success, and a recent study of parents' experiences identified the most common goal as being to 'have no regrets' (Cote-Aresenault, 2016). Recent reflections of a bereaved mother have also been published in an article entitled Palliative Care is not just for the Dying, in which she described the importance of perinatal palliative care for her family (Tadorovic, 2016). Her story acts as a powerful reminder of the importance of addressing the needs of siblings and parents, whilst keeping the baby at the centre of decision making.

What NICE (2016) said about research in perinatal palliative care – There is little evidence on the experience families have of the death of a baby with or without specific support from a perinatal palliative care team. Individual case reports on family experience are very positive about perinatal palliative care, but published evidence is scarce.

Appendix three: Glossary of key terms

Advance Care Plan

A formal care plan that includes details about the baby's condition, decisions made with their parents or carers (for example, about managing symptoms), and their wishes and ambitions. This plan is a core element of their palliative care.

Children's hospice services

Children's hospice services provide palliative care for babies, children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services. Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose-built building.

End of life care

End of life care helps babies with advanced, progressive, incurable illness to live as well as possible until they die. 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 supportive and palliative care needs of both baby and family to be identified and met throughout the last stage of the baby's life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and bereavement support for the family. This is not confined to specialist services but includes services provided by any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the baby's care, or other carers who are acting in the role of parents.

Life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which a baby, child or young person will die.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be possible but can fail.

Neonatal units

Level one units provide special care for the local population. Depending on local arrangements, they may also provide some high dependency care. Level two units provide special care and high dependency care. Level three units provide the whole range of medical (and sometimes surgical) neonatal care for the local population from a larger intensive care unit. Many will be sited within perinatal centres that are able to offer similarly complex obstetric care. These units will also require close working arrangements with all of the relevant paediatric sub-specialties.

Neonates

Babies aged up to 28 days.

Parallel planning

Planning for end of life care while taking account of the often unpredictable course of life-limiting conditions. It involves making multiple plans for care, and using the one that best fits the baby's circumstances at the time.

Parents

The term 'parents' is used to mean any carer for a baby whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Perinatal palliative care

Perinatal palliative care involves providing integrated ongoing support from the diagnosis of a life-limiting condition in a fetus, and during pregnancy, delivery, postnatal care, and (if needed) bereavement care.

Appendix four: References

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Appendix five: Directory of useful organisations

Listed below are some of the national organisations that provide support for babies with life-limiting conditions and their families. There are many others and this is by no means an exhaustive list. Please call Together for Short Lives helpline on 0808 8088 100 for details of other sources of support.

Neonatal and birth specialists

Antenatal Results and Choices (ARC)
ARC provides support and information to expectant and bereaved parents throughout and after antenatal screening.

www.arc-uk.org
Tel: 020 7713 7486
Helpline: 0845 077 2290
Email: info@arc-uk.org

Bliss
Bliss is the special care baby charity which provides vital support and care to premature and sick babies across the UK. Bliss offers guidance and information, funds ground-breaking research and campaigns for babies to receive the best possible level of care regardless of when and where they are born.

www.bliss.org.uk
Tel: 020 7378 1122
Helpline: 0808 801 0322
Email: hello@bliss.org.uk

Multiple Births Foundation
Multiple Births Foundation provides support and advice for families with twins or more.

www.multiplebirths.org.uk
Tel: 020 3313 3519
Email: mbf@imperial.nhs.uk

Perinatal Institute for maternal and child health
National non-profit organisation that aims to enhance the safety and quality of maternity care and provides resources for healthcare professionals.

www.perinatal.org.uk

Sands

Sands is the stillbirth and neonatal death charity. They operate throughout the UK, supporting anyone affected by the death of a baby, before or after birth, working to improve the care bereaved parents receive and promoting research to reduce the loss of babies' lives.

www.sands.org.uk
Tel: 020 7436 7940
Helpline: 0808 164 3332
Email: helpline@sands.org.uk

The Twins and Multiple Births Association (Tamba)

Tamba is a UK wide organisation helping parents of twins, triplets and more and professionals to meet the unique challenges that multiple birth families face. Their Bereavement Support Group provides support for families who have lost one or more children from a multiple birth, during pregnancy or at any stage afterwards.

www.tamba.org.uk
Tel: 01252 332 344
Helpline: 0800 138 0509
Helpline email: asktwinline@tamba.org.uk
General Email: enquiries@tamba.org.uk

Tiny Life

Tiny Life – Northern Ireland's premature and vulnerable baby charity, dedicated to reducing premature birth, illness, disability and death in babies. Tiny Life offer a range of support for families including support on the neonatal units, parent support groups and parent guides.

www.tinylife.org.uk
Tel: 028 9081 5050
Email: info@tinylife.co.uk

Tommy's

Tommy's exists to save babies' lives. They fund research into the causes and prevention of pregnancy complications that lead to miscarriage, stillbirth and premature birth. They also provide pregnancy health and information for parents to be.

www.tommys.org
Tel: 0800 0147 800
Email: mailbox@tommys.org

United Kingdom Association for Milk Banking (UKAMB)

Supports human milk banking and aims to provide safe and screened donor breastmilk for premature and sick babies.

www.ukamb.org

Organ donation

National Tissue Donor Referral Centre
Tel: 0800 432 0559
Email: national.referral.centre@nhsbt.nhs.uk

General support and information

Carers UK
Carers UK campaign to urge people to recognise the true value of carers' contribution to society and to ensure carers get the practical, financial and emotional support they need.

www.carersuk.org
Tel: 0808 808 7777
Email: info@carersuk.org

Citizens Advice Bureau (CAB)
The Citizens Advice service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers. Your local branch can be found on the website.

www.citizensadvice.org.uk
Adviceline England: 03444 111 444
Adviceline Wales: 03444 772 020

Contact
Contact are a national charity for families with disabled children. They provide information, advice and support. They bring families together so they can support each other. They campaign to improve their circumstances, and for their right to be included and equal in society.

www.contact.org.uk
Helpline: 0808 808 3555
Email: helpline@contact.org.uk

Disabled Living Foundation
A national charity that provides free, impartial advice about all types of equipment for disabled people. It can help you find products and suppliers and also has an equipment demonstration centre. They also produce factsheets and other information resources.

www.dlf.org.uk
Helpline: 0300 999 0004
Email: info@dlf.org.uk

Family Fund
The Family Fund helps families with severely disabled children to have choices and the opportunity to enjoy everyday life. They give grants for things such as washing machines, driving lessons, hospital visiting costs, computers and holidays.

www.familyfund.org.uk
Tel: 01904 550 055
Email: info@familyfund.org.uk

GOV.UK
A website to find government services and information. Including information on benefits and carers' rights.

www.gov.uk

Newlife the Charity for Disabled Children
Newlife Foundation helps disabled and terminally ill children in the UK by providing equipment to help individual children as well as providing nurse led information service and funding research. They have a special 'Just Can't Wait' equipment service for families of terminally ill children.

www.newlifecharity.co.uk
Tel: 01543 462 777
Nurse Helpline: 0800 902 0095.
Email: info@newlifecharity.co.uk

Paediatric Chaplaincy Network
Paediatric Chaplaincy Network is a group of multi faith religious and spiritual care staff and volunteers working in hospitals, hospices and the wider community.

www.paediatric-chaplaincy-network.org

Rainbow Trust Children's Charity
Rainbow Trust supports families who have a child aged 0-18 years of age with a life-threatening or terminal illness. They provide practical and emotional support to families.

www.rainbowtrust.org.uk
Tel: 01372 363 438
Email: enquiries@rainbowtrust.org.uk

REACT
REACT (Rapid Effective Assistance for Children with Potentially Terminal illness) is a dynamic charity working to improve the quality of life for financially disadvantaged children with life-limiting illnesses living in the UK. The charity provides grants and holidays.

www.reactcharity.org
Tel: 020 8940 2575
Email: react@reactcharity.org

Samaritans
Samaritans provides confidential non-judgmental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

www.samaritans.org.uk
Helpline: 116 123
Email: jo@samaritans.org

Sibs

Sibs supports siblings who are growing up with a brother or sister with any disability, long term chronic illness or life-limiting condition. They can provide information on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

www.sibs.org.uk

Email: info@sibs.org.uk

Working Families

Helps working parents, carers and their employers balance home and work responsibilities. They also provide information about parents' rights at work and to benefits after they experience miscarriage, stillbirth and neonatal death.

www.workingfamilies.org.uk

Condition specific information and support

Cerebra

Cerebra are the charity dedicated to helping families with children with brain conditions discover a better life together, through research, information and direct ongoing support.

www.cerebra.org.uk

Tel: 01267 244200

Helpline: 0800 328 1159

Email: info@cerebra.org.uk

Climb (Supporting those affected by inherited metabolic disorders)

Climb is committed to fighting metabolic diseases through research, awareness and support. For diagnosed and undiagnosed families with metabolic disease, they can supply long term support for all issues to do with diagnosis, treatment, benefit advice, small grants, family issues, bereavement and more.

www.climb.org.uk

Helpline: 0845 241 2173

Email: contact@climb.org.uk

Genetic Alliance UK

A national charity working to improve the lives of patients and families affected by all types of genetic conditions. An alliance of over 160 patient organisations, their aim is to ensure that high quality services, information and support are provided to all who need them.

www.geneticalliance.org.uk

Tel: 020 7831 0883

Email: www.geneticalliance.org.uk

Lagan's Foundation

A national charity providing support and at home care to families with babies and children under the age of five diagnosed with congenital heart defects.

www.lagans.org.uk

Tel: 01204 800 300

SWAN UK

SWAN UK (Syndromes Without A Name) is a project run by Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

www.undiagnosed.org.uk

Email: info@undiagnosed.org.uk

Bereavement

Baby Mailing Preference Service (MPS) online

Free site where parents can register online to stop or help reduce baby-related mailings.

www.mpsonline.org.uk/bmpsr

Child Bereavement UK

Child Bereavement UK supports families and educates professionals when a baby or a child of any age dies or is dying, or when a child is facing bereavement.

www.childbereavement.org

Tel: 0800 02 888 40

Email: support@childbereavement.org

Childhood Bereavement Network

The Childhood Bereavement Network seeks to ensure that all children and young people in the UK, together with their families and other care givers, including professional carers, can easily access a choice of high-quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

www.childbereavementuk.org/

Tel: 020 7843 6309

Email: cbn@ncb.org.uk

Cruse Bereavement Care

Cruse promote the wellbeing of bereaved people and helps them understand their grief and cope with their loss.

www.cruse.org.uk

Helpline: 0808 808 1677

Email: helpline@cruse.org.uk

Gifts of Remembrance

Provides photography training for hospital staff and volunteers who support parents after a stillbirth or neonatal death.

www.giftsofremembrance.co.uk

Mariposa Trust (also known as Saying Goodbye)
The charity supports anyone who has been affected by the loss of a child at any stage of pregnancy, at birth or in infancy.

www.mariposatrust.org

Tel: 0845 293 8027

Email: info@mariposatrust.org

Remember My Baby Remembrance
Photography
UK-based charity who have professional photographers who voluntarily provide their photography services to parents whose baby dies before, during or shortly after birth.

www.remembermybaby.org.uk

The Child Death Helpline
The Child Death Helpline is a helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.

www.childdeathhelpline.org

Helpline: 0800 282 986

Email: contact@childdeathhelpline.org

The Compassionate Friends UK
The Compassionate Friends is an organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children. They also offer support, advice and information to other relatives, friends and professionals who are helping the family.

www.tcf.org.uk

Helpline: 0345 123 2304

Email: helpline@tcf.org.uk

Winston's Wish
Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families, including for children after a death of a sibling.

www.winstonswish.org.uk

Helpline: 08088 020 021

Email: info@winstonswish.org.uk

Appendix six: Contacts for local services

You may find it helpful to make a note of useful local contact numbers below:

Name of unit or service caring for baby:

NICU Lead Consultant:

Key contact (Key Worker):

Neonatal Community Sister:

NICU Manager:

Midwife contact:

Obstetrician:

Community Children's Nursing Team:

GP:

Health visiting contact:

Spiritual support:

Palliative care team (hospital):

Hospice or community palliative care team contact:

Social work contact:

Physiotherapy contact:

Speech and language therapy contact:

Dietician:

Surgeon:

Gastroenterology contact:

Bereavement/psychological support:

Local charities:

General contacts:

Antenatal Results and Choices (ARC) helpline: 0845 077 2290

Sands helpline: 0808 164 3332

Bliss helpline: 0808 801 0322

Together for Short Lives helpline: 0808 8088 100

A Perinatal Pathway for Babies with Palliative Care Needs

The majority of child death happens in the first 28 days of life, the neonatal period. Every year, over 90,000 babies are admitted to neonatal intensive care in the UK. While many of these babies will only need to receive treatment for a few days or weeks before being discharged home, a minority will need more intensive care.

On average, there are 2,109 neonatal deaths each year from causes likely to require palliative care and currently 98% of these deaths occur in a hospital setting.

Together for Short Lives has recognised the need for a dedicated perinatal care pathway from the point of recognition that a baby may not survive for long after birth and through their neonatal period. The need for palliative care may be recognised during the pregnancy, at the prenatal 20-week scan, or may not become apparent until after a baby is born.

This Perinatal Pathway for Babies with Palliative Care Needs will be of interest to fetal medicine specialists, obstetricians, neonatal service providers, maternity services, including midwives and those working in the children's palliative care sector. It is also a resource that can be used by commissioners of services to ensure that the appropriate care and resources are available in the right place, at the right time and that care is delivered by the right people.

The emphasis throughout the document is that involving professionals working together across multi-disciplinary teams and services will provide the best response to families during a distressing and uncertain time.

Together for Short Lives hopes that this updated and extended care pathway will be a tool to encourage professionals to offer families timely choices in their care and to enable families to have the best possible experience and memory of their baby, no matter how short their life may be.



Together for Short Lives
New Bond House, Bond Street, Bristol, BS2 9AG

T: 0117 9897820
E: info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

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