Care Pathway for the Unborn Child, Neonate or Infant Diagnosed with potentially Life-limiting or Life-threatening Conditions

East Midlands Neonatal Operational Delivery Network
East Midlands Children's & Young Peoples Palliative Care Network

This pathway is dedicated to the memory of Eddie, Mia, Divine and all the babies, children and their families across the East Midlands who have inspired this project.

It is hoped that it will make a significant difference for babies, children and their families in the future.

Introduction

Together for Short Lives (2017) and NICE (2016) advocate a care pathway approach to ensuring the best possible quality of life, care and support for children (and their families) with life-limiting or life-threatening conditions.

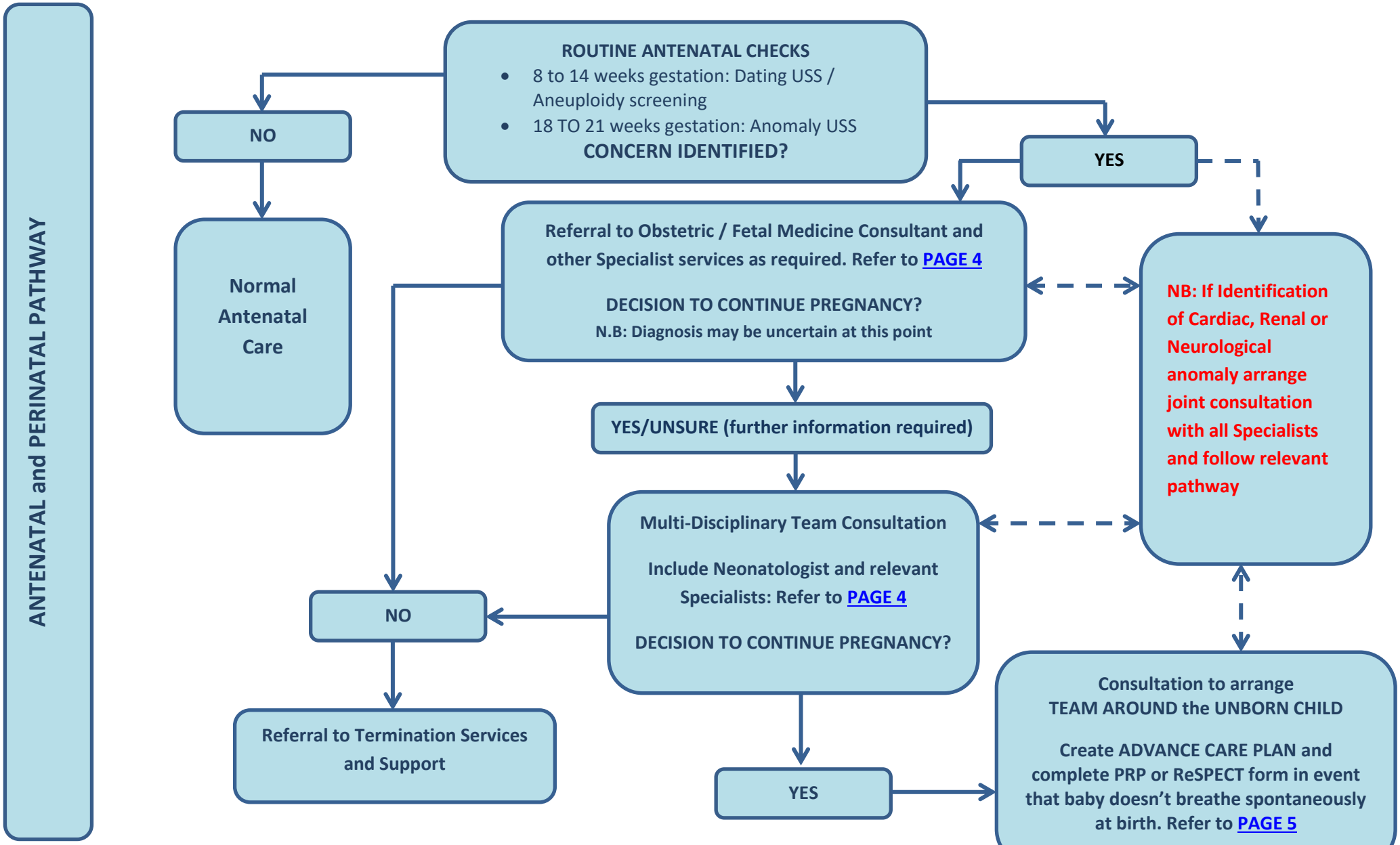
A condition which is life-limiting or life-threatening for a child (RCPCH, 2017) may be suspected or confirmed during the antenatal period, at birth or during the postnatal period. In such circumstances parents have a central role in decision-making and care planning. (NICE, 2016). Families should be informed of the support available to them from the outset. This will enable them to make choices about the elements of the service they wish to access at different points throughout their journey (Together for Short Lives, 2017).

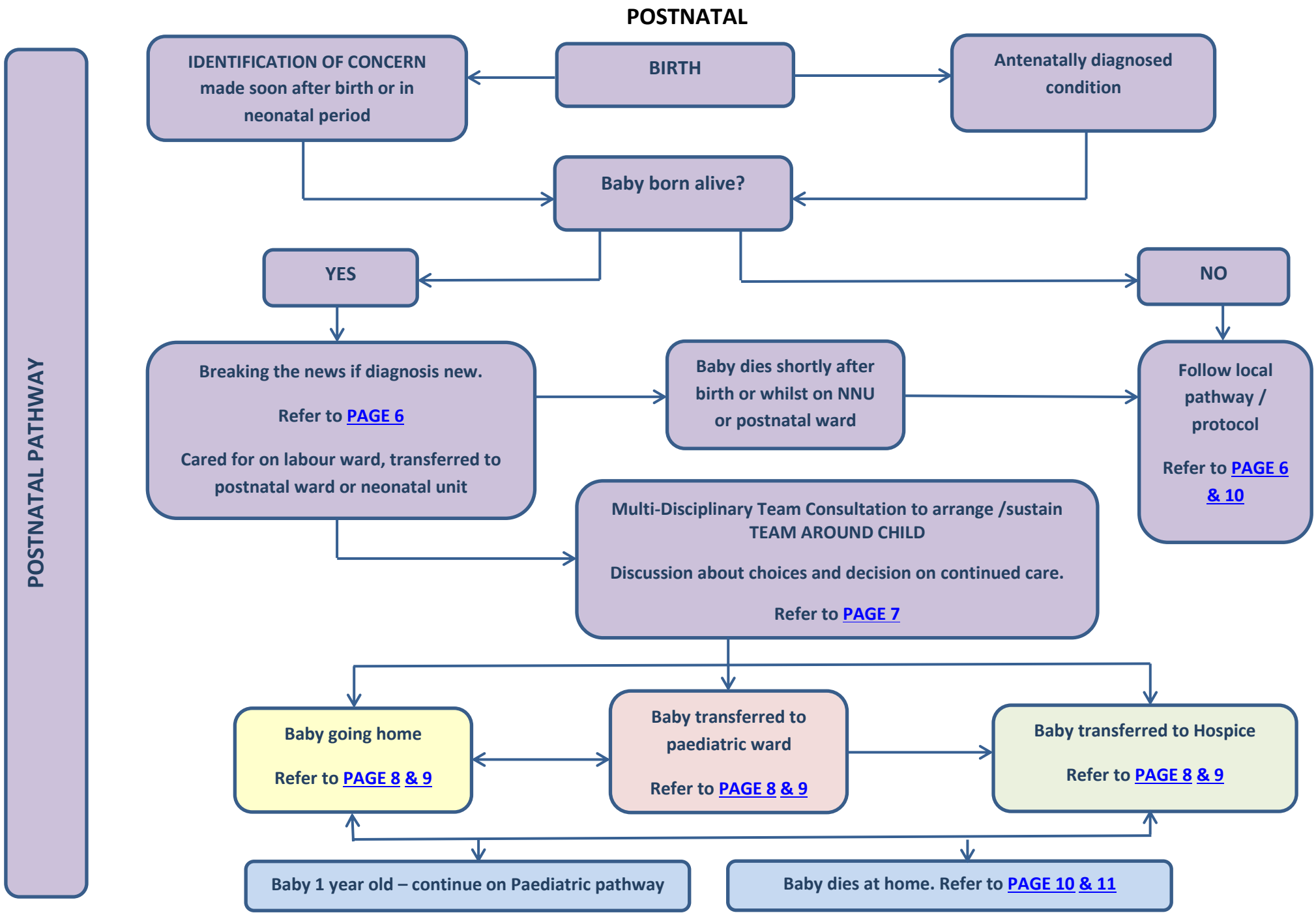
This pathway is intended to support the care of the unborn child, neonate or infant up to the age of 1 year, and the family, when a life-shortening or life-threatening condition is suspected or diagnosed (See Appendix 1).

It is intended to assist the multi-disciplinary team to deliver supportive and/or end of life care which is consistent and coordinated across care settings – hospital (maternity, neonatal and paediatric), home and hospice. Family choices for their infant's management may change during their journey of care. The pathway should be used to ensure seamless transition between the care settings but can also support the transition from active to palliative care in any setting.

The pathway is intended as a regional Network document and therefore reflects the fact there will be some variation in services and facilities available across the region. It is important that the resources accessible locally are understood and communicated to families on an individual basis.

ANTENATAL and PERINATAL




POSTNATAL
POSTNATAL PATHWAY
IDENTIFICATION OF CONCERN made soon after birth or in neonatal period
BIRTH
Antenatally diagnosed condition
Baby born alive?
YES
NO
Breaking the news if diagnosis new.
Refer to PAGE 6
Cared for on labour ward, transferred to postnatal ward or neonatal unit
Baby dies shortly after birth or whilst on NNU or postnatal ward
Follow local pathway / protocol
Refer to PAGE 6 & 10
Multi-Disciplinary Team Consultation to arrange /sustain TEAM AROUND CHILD
Discussion about choices and decision on continued care.
Refer to PAGE 7
Baby going home
Refer to PAGE 8 & 9
Baby transferred to paediatric ward
Refer to PAGE 8 & 9
Baby transferred to Hospice
Refer to PAGE 8 & 9
Baby 1 year old – continue on Paediatric pathway
Baby dies at home. Refer to PAGE 10 & 11

Antenatal & Perinatal Pathway: Information & Choices

Routine Antenatal Screening

- Written information on antenatal testing given to family (See Appendix 2)
- Information on how and when test results will be given and by whom, is provided to family
- Antenatal Results and Choices (ARC) booklet is given as appropriate (See Appendix 2)

Concern Identified: Referral

N.B: Diagnosis may be unclear at this point

- Refer to local pathway for Antenatally Diagnosed Foetal Anomaly
- Family notified of concern as per local pathway
- **NB: if specific anomaly identified, such as cardiac, renal, neurological, follow relevant pathway for that anomaly, ensuring multidisciplinary involvement**
- Further investigations may be required / requested
- Consider referral to other agencies, specialists and / or hospitals as necessary.
- Condition may be identified as life threatening / life shortening (see Together for Short Lives Perinatal Pathway, 2017; RCPCH, 2015; BAPM, 2010)
- Inform Community Midwife and GP
- Support to family at this time is most likely to be through the Community Midwife however support can be sought from Foetal Medicine team or other specialists as required.

Concern is identified as life threatening or life limiting

MDT Consultation: Breaking the News and Follow Up

- Family contacted and asked to attend consultation with professionals at next available appointment i.e. **as soon as possible**
- Consultation with family to include (as required): -
  - Consultant: foetal medicine, neonatology and relevant specialists e.g. genetics, cardiology
  - Specialist Midwife and/or Community Midwife, Specialist Nurse(s) in life-limiting / life threatening condition
  - Pregnant mother
  - Father or designated support person
  - Interpreters as required
- Follow up visit / telephone call as arranged to answer questions and discuss concerns
- Decision made by family whether to continue with pregnancy or not

Check:

- ✓ **Provide information on condition, probable prognosis for baby, best and worst case scenarios, continuation or termination of pregnancy at earliest appropriate opportunity**
- ✓ **Point of contact details of are given to family**
- ✓ **Written material and/or useful website addresses given as appropriate**
- ✓ **Information shared with Community Midwife, GP, Health Visitor, Hospice, Children's Community Nursing Team**
- ✓ **Arrangements made for Follow Up and support as appropriate**

Antenatal & Perinatal Pathway: Planning & Management

Develop Team around Unborn Child

- All babies with a life limiting condition should be under the care of a named medical specialist in hospital and on discharge who can review their medical care plans promptly as needed
- **Multi-Disciplinary Team Consultation to arrange team around unborn child**. To include **as appropriate:**
    - Consultants – Foetal medicine, neonatology and specialists in life-limiting / threatening condition
    - Foetal Medicine Midwife and / or Community Midwife, Specialist Nurse(s)
    - Pregnant mother
    - Father / designated support person
    - Children's Community Nursing Team, Specialist paediatric palliative care team (NICE, 2016), Hospice and / or Bereavement Nurse / Midwife, - **as appropriate**
    - Counselling services if available
    - Interpreters as required
    - Spiritual and emotional support
- Referral into Neonatal ALERT Folder

Check:

- ✓ **KEY WORKER is appointed where applicable, and process for communication identified, including contact details**
- ✓ **NAMED MEDICAL SPECIALIST and NAMED NURSE are identified**
- ✓ **Discussion about condition, possible outcomes and choices**
- ✓ **Choices continue to be explored with family - to include Hospice care as appropriate**
- ✓ **Arrangements for Antenatal care continued**
- ✓ **ADVANCE CARE PLAN (see example in Appendix 3) written – this may change with on-going discussions and agreements with family. NB: This plan is IN ADDITION to (not in place of) any ReSPECT form**
- ✓ **Emotional and spiritual support put in place as appropriate – to include support for siblings**
- ✓ **Next meeting arranged and any follow up meetings as required**
- ✓ **Contact details for key worker(s) given to family**
- ✓ **Referral to neonatal team, including neonatal outreach as appropriate**
- ✓ **Visits to neonatal unit and/or other specialist units e.g. cardiac, neuro, hospice arranged as required**
- ✓ **Introduction to Hospice Team and Child Bereavement Team as appropriate**
- ✓ **System in place to ensure regular liaison between all professionals**
- ✓ **Information updates provided to GP/Community Midwife/Health Visitor/Social worker**

Develop Advance Care Plan

- Discuss choices and develop **ADVANCE CARE PLAN at the earliest opportunity**.
- Complete **PERSONAL RESUSCITATION PLAN (PRP)** and / or **ReSPECT form**

DOCUMENTS TO BE KEPT IN MOTHER'S HAND HELD NOTES to ensure that when mother goes into labour the discussed and agreed plan can be implemented. A copy should be filed in **Medical Records** (NICE, 2016). The plan may change and should be updated in discussion and agreement with family. A new document must be filed in **Hand Held Notes and Medical Records** whenever changes are agreed – this will be the definitive document. Choices in this document **MUST** be communicated to all involved with family's care

Postnatal Pathway

Baby born: Concern identified shortly after birth or in neonatal period

N.B: Diagnosis may be unclear at this point

Breaking the News

- Clinical assessment may be completed on labour suite or neonatal unit. Consider liaison with any specialists required.
- Discussion about possible withdrawal of intensive care **if appropriate**
- Meeting with family to include:
  - Neonatal Consultant, and specialist consultant(s) as appropriate
  - Family care team member or midwife / neonatal nurse caring for baby (if available), Specialist Nurse(s) in life-limiting / life threatening condition
  - Mother
  - Father or designated support person, family / friend
  - Interpreters, if required
  - Other members of MDT **as appropriate** such as Bereavement Midwife, Children's Community Nursing Team , Specialist paediatric palliative care team, Hospice Team

Check:

- ✓ **Information given to family about condition and possible outcomes for baby**
- ✓ **Written information on options given and discussed e.g. Hospice, Community care**
- ✓ **Useful website addresses and signposting provided to family**
- ✓ **Contact details of professionals given to family**
- ✓ **Consultation with family to identify TEAM AROUND CHILD arranged**
- ✓ **Opportunities for 'making memories' provided and facilitated. See Appendix 2**

Baby dies shortly after birth or whilst on NNU or postnatal ward

If baby dies shortly after birth or prior to transfer for continuing care check:

- ✓ **Follow local pathway**
- ✓ **Is post-mortem required?**
- ✓ **Is referral to Genetics required?**
- ✓ **Consider organ donation if appropriate (Family wishes, >36/40, >2.5kg) See Appendix**
- ✓ **Would family like baby transferred to Hospice?**
- ✓ **Consider staff debrief**

Postnatal Pathway continued

Meeting to develop or sustain TEAM AROUND CHILD

- Meeting to include:
  - Family
  - Neonatal Consultant, and specialist consultant(s) as appropriate
  - Midwife (as appropriate), Specialist Nurse(s) in life-limiting / life threatening condition
  - Family care team (if available)
  - Child Bereavement Team (as appropriate)
  - Interpreters, if required
  - Other members of MDT as appropriate e.g. Local paediatrician as applicable, GP, Children's Community Nursing Team, Specialist paediatric palliative care team, Hospice Team, Chaplain
- Discuss with family about choices for **on-going care** (e.g. choices where family want to spend time with baby prior to withdrawal of care, whether family want baby to stay on NNU or transfer to hospice if death is imminent). Discuss all possible scenarios and produce parallel plans (plans for on-going care alongside plans for end of life care) for each eventuality
- Consider early involvement of Hospice Staff – attendance on ward rounds etc.
- Plans and decisions to be documented in **ADVANCE CARE PLAN** (see example in Appendix 3)
  N.B: The plan may change and require updating as baby's condition changes.

Check:

- ✓ **KEY WORKER, NAMED MEDICAL SPECIALIST and NAMED NURSE identified if not already established**
- ✓ **ADVANCE CARE PLAN updated and includes PRP and / or ReSPECT form, Parallel plans, treatment plans, symptom control, family choices as appropriate. Ensure updates are communicated to all involved with family's care.**
- ✓ **End of life plan included if death imminent – follow local pathway / guidelines**
- ✓ **Information and contact details given to family**
- ✓ **Emotional and spiritual support in place as appropriate – to include support for siblings**
- ✓ **Arrangements made for continued postnatal care for mother as required**
- ✓ **Bereavement support provided as required**
- ✓ **Next meeting arranged with family**
- ✓ **All other professionals involved with family and /or infant (GP, Health Visitor, Midwife, Child Death Review Team etc.) are informed of status of infant, plans for care and possible outcomes**

Discussion of choices and decision on continuing care

Baby's death is not imminent but is foreseeable in short, medium or long term.

Discussion with family about choices for continuing care: **paediatric ward, home or hospice**. This decision should be dependent on condition of baby and what is best for baby and family.

When developing plans for the care of the infant with a life-limiting condition, use **parallel planning** to take account of possible unpredictability in the course of the condition.

Postnatal Pathway continued

BABY GOING HOME:

Key worker to arrange discharge planning meeting and initiate referral to community follow up teams:

- Palliative care team if death imminent (24 hour if available)
- Children's Community Nursing Team
- Lead Paediatrician
- Children's continuing care if appropriate
- Any other locally available palliative care support teams / clinicians
- Named medical specialist to see baby **at home** as soon as possible

BABY GOING TO PAEDIATRIC CARE:

Key worker to make referral to:

- Consultant on Paediatric ward
- Ward nursing staff as appropriate
- Introduce family to ward staff and environment
- Arrange date and time for transfer

BABY GOING TO HOSPICE:

Key worker or other relevant staff member to make **TELEPHONE** referral to:

- Appropriate Hospice:
  - Rainbows Hospice (01509 638000)
  - Bluebell Wood (01909 517369)
- Arrange transfer **in liaison with Hospice staff.**

FOR ALL PATHWAYS (unless otherwise indicated by path specific highlight)

Multidisciplinary TEAM AROUND CHILD to include:

- Family: Mother, Father and if required nominated support family member or friend
- Key worker / Named medical specialist
- Community nurses and Specialist paediatric palliative care team where available
- Child Bereavement Team
- Health visitor
- GP
- Interpreters as required
- Hospice staff as applicable
- Neonatal Consultant and other relevant medical staff
- Neonatal Family Care / Outreach / Children's Community Nursing Team as appropriate
- Neonatal Transport Team as appropriate. See Appendix 2
- Paediatric Consultant and ward staff as appropriate
- Local paediatrician as applicable
- Child and family support services

Postnatal Pathway continued

FOR ALL PATHWAYS

KEY WORKER OR NAMED MEDICAL SPECIALIST to check:

- ✓ **Discharge planning meeting arranged where appropriate**
- ✓ **Arrangements for safe transfer of baby**
- ✓ **ADVANCE CARE PLAN and PRP and / or ReSPECT form made, reviewed and updated as required. Plan to be held by family**
- ✓ **Parallel plans and referrals to alternative pathways made as required**
- ✓ **Lead paediatrician - on ward or in community as applicable - appointed and contact details available**
- ✓ **Emotional support for family available**
- ✓ **Sibling Support**
- ✓ **Spiritual and cultural needs being met as required**
- ✓ **Professionals who may be involved in baby's care identified and informed – e.g. GP, Health Visitor**
- ✓ **Child Death Review Team**
- ✓ **Training for use of equipment provided as required**
- ✓ **Treatment and therapies arranged as appropriate**
- ✓ **Plans for symptom control made and communicated**
- ✓ **CHOICES document discussed with family again as required**
- ✓ **Access to Benefits as appropriate**
- ✓ **Information given**
- ✓ **Opportunities for 'making memories' provided and facilitated. See Appendix 2**

In addition for BABY AT HOME:

- ✓ **Home visit arranged within 24 hours of transfer**
- ✓ **Next meeting arranged with family**
- ✓ **Lead Community Children's Nurse identified for on-going nursing needs and referral**
- ✓ **Specialist paediatric palliative care team**
- ✓ **24 hour cover arranged as appropriate**
- ✓ **24/7 Contacts in place for family if concerns arise**
- ✓ **Named medical specialist reviews regularly at least every 14 days**
- ✓ **Anticipatory medication and care plan available**
- ✓ **Equipment and supplies provided and arrangement for replenishment made**
- ✓ **Training for use of equipment at home provided**
- ✓ **Help given to access potential home adaptations, short breaks and special educational support as appropriate and required**

Pathway for End of Life at Home

Recognition of end of life for baby at home

Ensuring Quality of Life and that the End of Life is as peaceful as possible

Review meeting to be held to discuss needs and wishes of family and baby. Smaller, more intensively involved team and more support in the home may be required.

Review meeting to include:

- **KEY WORKER – ESSENTIAL TO EFFECTIVE COMMUNICATION**
- Named Medical Specialist
- Named Nurse
- Family: Mother, Father and nominated support family member or friend if required
- Children's Community Nursing Team, Specialist paediatric palliative care team
- Child Bereavement Team as available and appropriate
- Hospice staff if applicable
- Health Visitor
- Community paediatrician and/or GP
- Chaplains as applicable
- Interpreters as required

Check:

- ✓ **Plan for End of Life. Discussion again with family on Choices document. Adjust plans accordingly.**
- ✓ **End of Life plan to include Care of Baby AFTER death (where and how long), informing of other family and friends of death (who, how and when) and consider discussion of organ donation**
- ✓ **PERSONAL RESUSCITATION PLAN and / or ReSPECT form completed or amended**
- ✓ **Referral made to 24 hour Community Palliative Care Team if available**
- ✓ **Registration with and notification to Ambulance Service *N.B: If baby is at home and expected to die care plan should include NOT dialling 111/999 as if call is processed through either system an ambulance response will be generated. This will lead to CPR and blue light transfer unless clearly stated in the PRP that resuscitation is NOT required.***
- ✓ **Plans made for regular pain and symptom review**
- ✓ **Availability of anticipatory medication and plan of care for when the baby deteriorates**
- ✓ **Parallel plan and review for if the baby stabilises**
- ✓ **Arrangements made for emergency prescribing of medications and out of hours pharmacy needs**
- ✓ **Consider referral to Hospice if not already in place**
- ✓ **On-going postnatal care for Mother as required**
- ✓ **Support for family including sibling support**
- ✓ **Continuity of care for family throughout this time – to include making memories and keepsakes. See Appendix 2**
- ✓ **Spiritual, religious and cultural needs are met**
- ✓ **Transport arrangements in place**
- ✓ **Contact details given to family**

Pathway for End of Life at Home continued

Continued Bereavement Support after death whether baby died at home, in hospital or in hospice

Follow up by TEAM AROUND CHILD (in community) or KEY WORKER (in hospital) to ensure:

- Support family in contacting GP to certify death
- Child Death Overview Team notified of death
- Coroner is aware and whether a Post Mortem is required and if coroner is to take the case
- Information on choices are given to, and discussed with, family to allow family to maintain control
- Emergency plans are cancelled as applicable
- Support mechanisms for all family members are in place e.g. counselling arranged. N.B: Rainbows have a counsellor and any family who have been referred to Rainbows can access this.
- Contact details given to family
- Equipment and deliveries of supplies are cancelled (or family made aware if cancellation not possible immediately)
- Registration of birth and death
- Funeral arrangements
- Spiritual, religious and cultural needs are being met
- On-going postnatal care for Mother as applicable
- Transport arrangements are in place if required
- Arrangements for long term support are made
- Follow up meeting with medical professionals is arranged
- Seek feedback from families. See Appendix 5
- Staff debrief arranged as required (see below)

All pathways - Staff debrief

Support and debrief should be offered to **ALL medical, nursing and support staff** as applicable (i.e. obstetric / community / paediatric) in line with local arrangements. These may include:

- Group debrief
- One to one debrief
- Clinical supervision
- Counselling

AUDITABLE STANDARDS

	AUDIT STANDARD		TARGET		
			Audit 1	Audit 2	Audit 3
ANTENATAL PATHWAY	1.	There is evidence that the unborn child, neonate or infant diagnosed with life threatening or life limiting condition has a **Named Medical Specialist**	60%	80%	100%
	2.	There is evidence that the unborn child, neonate or infant diagnosed with life threatening or life limiting condition has an **Advance Care Plan** filed in the medical records	60%	80%	100%
	3.	There is evidence that the unborn child, neonate or infant diagnosed with life threatening or life limiting condition has a **Personal Resuscitation Plan and/or ReSPECT form** completed	60%	80%	100%
POSTNATAL PATHWAY	4.	There is evidence that there have been discussions about **choices for continuing care** with the family of the neonate or infant diagnosed with life threatening or life limiting conditions.	60%	80%	100%
	5.	There is evidence that the **Advance Care Plan has been updated**.	60%	80%	100%
	6.	There is evidence that on-going **psychological and/or bereavement support** is available to the family	60%	80%	100%
	7.	There is evidence of on-going **training in palliative care** for the Multi-Disciplinary Team as defined in Appendix 2	60%	80%	100%

- These standards will be audited every 2 years
- Results will be presented to the East Midlands Childrens & Young Peoples Palliative Care Network (EMCYPPCN) Board, East Midlands Neonatal Network Clinical Governance Groups and Network Boards
- Where results show the FINAL (100%) audit standards have not been met an action plan will be required and a timeframe for re-audit identified as applicable.

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Organisations and Groups included in Consultation Process:

Group	**Organisation**
East Midlands Children's and Young Peoples Palliative Care Network (EMCYPPCN)	EMCYPPCN
Rainbows Hospice, Loughborough, Leics	Rainbows Hospice
Central Newborn Network Board	Central Newborn and Trent Perinatal Networks Operational Delivery Network (ODN)
Trent Perinatal Network Board	Central Newborn and Trent Perinatal Networks Operational Delivery Network (ODN)
Derby Teaching Hospitals NHS Foundation Trust	Derby Teaching Hospitals NHS Foundation Trust
Kettering General Hospital NHS Trust	Kettering General Hospital NHS Trust
Leicestershire Partnership NHS Trust	Leicestershire Partnership NHS Trust
Northampton General Hospitals NHS Trust	Northampton General Hospitals NHS Trust
Northamptonshire Healthcare Foundation Trust	Northamptonshire Healthcare Foundation Trust
Nottingham University Hospitals NHS Trust	Nottingham University Hospitals NHS Trust
Nottinghamshire Healthcare NHS Foundation Trust	Nottinghamshire Healthcare NHS Foundation Trust
Sherwood Forest NHS Hospitals Trust	Sherwood Forest NHS Hospitals Trust
United Lincoln Hospitals NHS Trust	United Lincoln Hospitals NHS Trust
University Hospitals of Leicester NHS Trust	University Hospitals of Leicester NHS Trust
Clinical Governance Group & Clinical Forum	Central Newborn Network
Clinical Governance Group & Clinical Forum	Trent Perinatal Network
Parent Advisory Group (PAG)	Central Newborn Networks

Parent Advisory Group (PAG)	Trent Perinatal Network
Joint Lead Nurses and Matrons Forum	Central Newborn and Trent Perinatal Networks Operational Delivery Network (ODN)
Joint Education Forum	Central Newborn and Trent Perinatal Networks Operational Delivery Network (ODN)
East Midlands Childrens Clinical Steering Group	NHS England East Midlands
East Midlands Fetal Medicine Clinical Network	NHS England East Midlands
East Midlands Maternity Clinical Steering Group	NHS England East Midlands
Diana Community Childrens Service,	Leicestershire Partnership NHS Trust
Specialist Children's Nursing Team	Northamptonshire Healthcare Foundation Trust
CenTre Neonatal Transport Service	CenTre Neonatal Transport Service
East Midlands Ambulance Service (EMAS)	East Midlands Ambulance Service
Local Maternity Systems (LMS) Board	Derbyshire
Local Maternity Systems (LMS) Board	Leicestershire
Local Maternity Systems (LMS) Board	Lincolnshire
Local Maternity Systems (LMS) Board	Northamptonshire
Local Maternity Systems (LMS) Board	Nottinghamshire
Public Health and Children's Integrated Commissioning Hub	Nottinghamshire County Council

APPENDIX 1: Life-shortening and Life-threatening Conditions (RCPCH, 2017; Together for Short Lives, 2017):

The categorisation of illness (RCPCH, 2017; Together for Short Lives, 2017) is important to the planning and needs assessment of palliative care. The need for palliative care must always be assessed on an individual basis.

Definitions (Larcher et al on behalf of RCPCH, 2017):

Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die.

Life-threatening conditions are those for which curative treatment may be feasible but can fail. These will include the infant: -

a. with advanced progressive incurable disease
b. whose death is expected in the foreseeable future
c. in whom there is a risk of death from a sudden acute crisis in the condition
d. in whom sudden catastrophic events have produced a life-threatening situation
e. in whom the prospect of survival is small, for example, some extremely premature infants

Categories (Together for Short Lives, 2017):

CATEGORY 1	**Life threatening conditions for which curative treatment may be feasible but can fail** 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 *E.g. Extreme prematurity, severe necrotising enterocolitis, some types of congenital heart disease*
CATEGORY 2	**Conditions where premature death is inevitable** There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities *E.g. Chromosomal abnormality, severe spina bifida*
CATEGORY 3	**Progressive conditions without curative treatment options** Treatment is exclusively palliative and may commonly extend over many years *E.g. Severe bilateral multi-cystic kidneys, bilateral renal agenesis, anencephaly, skeletal dysplasia, severe neuromuscular disorders*
CATEGORY 4	**Irreversible but non progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death** *E.g. Severe hypoxic ischaemic encephalopathy*

Appendix 2: RESOURCES

A. HYPERLINKS TO RESOURCES AND ADDITIONAL INFORMATION for PARENTS and STAFF

- Together for Short Lives – www.togetherforshortlives.org.uk
- ARC: Antenatal Results and Choices - www.arc-uk.org
- British Association of Perinatal Medicine – www.bapm.org
- Rainbows Hospice – www.rainbows.co.uk
- SANDs – Stillbirth And Neonatal Death - www.sands.org.uk
- BLISS – www.bliss.org.uk
- Child Bereavement Trust – www.childbereavementuk.org
- Laura Centre – www.thelauracentrecandw.org.uk
- Religious and Cultural support services such as:
  - Muslim Burial Council – www.mbcol.org.uk
- ReSPECT – insert link to ReSPECT form
- Bereavement photography – www.remembermybaby.org.uk

B. TRANSPORT SERVICES:

- CenTre Transport Service – http://www.centreneonataltransport.nhs.uk
- East Midlands Ambulance Service (EMAS)

N.B: Professionals should contact either of the above transport services to discuss on a case by case basis as applicable.

C. LOCAL RESOURCES

A Directory of Contacts is available through the professionals 'tab' on the Rainbows website – www.rainbows.co.uk

D. MAKING MEMORIES

Families should be supported to create individual memories that are personal to them as a family. This may include photographs, videos, hand & footprints, written journals and scrap booking.

It is important that professionals working closely with a family understand their hopes and dreams and are able to support the family to capture special moments whether the baby is cared for in hospital, hospice or at home.

E. STAFF TRAINING

Provision for staff training in palliative care varies across the region. NICE (2011) states that Health and social care workers should have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers. Although this standard refers to 'End of Life care for Adults' the principles must also apply to children and neonates. Therefore it is expected that:

- There is evidence of local arrangements to ensure that health and social care workers involved in the care of the unborn child or neonate diagnosed with life-limiting or life threatening conditions receive training appropriate to their role. The education and training should incorporate dealing with loss, grief and bereavement and basic aspects of spiritual care for families of all faiths and none.

The following groups offer education and training:

- SANDS - www.sands.org.uk
- Rainbows Hospice - www.rainbows.co.uk . Training is free of charge but staff need to be released to attend.
- Child Bereavement Trust – www.childbereavementuk.org

Also follow links from local websites.

F. HOSPICES

Rainbows Hospice, Loughborough, Leics – www.rainbows.co.uk

Bluebell Wood Hospice, North Anston, Sheffield – www.bluebellwood.org

East Anglia Childrens Hospice (EACH), Ipswich – www.each.org.uk

APPENDIX 3: ADVANCE CARE PLAN EXAMPLE TEMPLATE

ORGANISATION / HOPSITAL LOGO				
EXAMPLE: ADVANCE CARE PLAN **Please keep this plan with you at all times**				
Date Advance Care Plan created:				
Baby's Details				
Surname:		**Hospital Number:**		
		NHS Number:		
Forename:		**Date of birth:**		
Home address:				
BACKGROUND: Diagnosis and summary of life limiting / threatening condition				
Family Contact Details				
	Name		**Contact details**	
Mother				
Father				
Parental responsibility				
	Relationship to infant:			
Comments				
Contact Details for Relevant Professionals				
Title	**Name**		**Contact details**	
Key worker				
Lead Consultant				
GP				
Health Visitor				
Preferred place of care (please circle)**:**	**Hospital**	**Home**	**Hospice**	
Completed by - Print name & Sign:				

ADVANCE CARE PLAN Please keep this document with you at all times		
Date and time:	**Plan to include:**	**Print name & sign:**
	• Plan for care following discussion of choices between family and clinicians • Information given to family • An agreed approach to communicating with and providing information to the child or young person and their parents or carers • Outline of the parent's wishes for their infant, for example on: - how to incorporate their religious, spiritual, and cultural beliefs and values into their infant's care - Record of significant discussions with parents or carers - Agreed treatment plans and objectives e.g. monitoring foetus ante- / peri- natally - Education plans for parents if applicable - Record of any discussions and decisions that have taken place on (delete as appropriate): - preferred place of care and place of death - organ and tissue donation (see recommendations NICE, 2016) - management of life-threatening events, including plans for resuscitation or life support and whether want to go into hospital / not - specific wishes, for example on funeral arrangements and care of the body • A distribution list for the Advance Care Plan.	
This plan has been discussed with:		
Consultant (print name and sign)		
This plan does not time expire but will be reviewed regularly and any changes recorded below		

<table>
<tr><th colspan="3">ADVANCE CARE PLAN UPDATE
Please keep this document with you at all times</th></tr>
<tr><td>Date and time:</td><td>Update the Advance Care Plan when needed, for example if:
new professionals become involved
care setting changes (for example hospital admission or discharge)
Infant and their parents or carers move home.
Discuss the changes with parents or carers.</td><td>Print name & sign:</td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>Update has been discussed with:</td><td colspan="2"></td></tr>
<tr><td>Print name and sign:</td><td></td><td></td></tr>
<tr><td colspan="3"></td></tr>
<tr><td></td><td>Plan update:</td><td></td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>Update has been discussed with:</td><td colspan="2"></td></tr>
<tr><td>Print name and sign:</td><td colspan="2"></td></tr>
</table>

APPENDIX 4: Good Practice Points: End of Life Care - when parents and healthcare professionals cannot agree what is in the infant's best interests.

Introduction

Decisions about on-going treatment for infants with life threatening or life limiting conditions are usually made between healthcare professionals and parents. Parents should be included in all discussions about an infant's prognosis and full explanations of potential outcomes outlined. When medical staff believe further treatment is futile this decision should be discussed with parents at the earliest opportunity and parent's views taken into account. If parents and healthcare professionals are initially unable to agree on what is in the infant's best interests it is hoped that clear and repeated communication will achieve a shared decision (Willems, 2014).

However, where this cannot be achieved despite continued communication, there should be a structured process in place to achieve a plan of care which is in the infant's best interests, and which makes provision for support for the parents and healthcare professionals during the process.

Scope of Practice

These good practice points have been produced for use in Neonatal Units across the East Midlands Neonatal Network and where applicable, as part of the 'East Midlands Care Pathway for the Unborn Child or Neonate Diagnosed with potentially Life-limiting or Life-threatening Conditions'.

These good practice points are intended to support a consistent approach to managing situations where parents and healthcare professionals are unable to reach a shared decision about End of Life care which is in the infant's best interests.

Good Practice Points

- Treatment should be continued throughout the process until an outcome is reached.
- If there is uncertainty about the infant's condition and outcome, treatment should be continued until there is greater certainty (RCPCH, 2017).
- Communication between parents and healthcare professionals should be maintained throughout the process. It may be useful for local Patient Advice and Liaison Services (PALS) and Chaplaincy staff to be involved and support the communication process.
- All communication and decisions relating to the situation must be documented and a copy of the documentation filed in the infant's medical record.
- There should be a treatment plan in place should the infant deteriorate unexpectedly. Parents must be aware of this plan.
- Healthcare professionals must follow the appropriate Trust protocols for escalation in such circumstances, seeking guidance from departments such as Communications, Legal and Clinical Ethics Services, as necessary.
- All media enquiries must be referred to the Trust Communications teams
- The family's GP and Health Visitor must be kept informed of the process and included in communication updates.

- Healthcare professionals should notify the Neonatal Operation Delivery Network (ODN).
- Second opinions and support if required should be sought from the Lead Centres for the Network. In the instance of a case being in Nottingham this should be Leicester and vice versa
- Support and clinical supervision can also be provided by the Network Lead Clinician and Lead Nurse
- Healthcare professionals should consult Professional bodies for advice e.g. BAPM, RCPCH Ethics and the Law Advisory Committee (ELAC).
- Arrangements should be made to provide psychological support for parents.
- Arrangements should be made to provide psychological support for staff.
- A debrief session should be arranged for all staff involved in the case on conclusion of the process.

References and Bibliography

- **British Association of Perinatal Medicine (BAPM) (2010).** *Palliative Care (Supportive and End of Life Care): A Framework for Practice in Perinatal Medicine.* BAPM, London.

- **Campbell, AGM; McHaffie, HE. (1995).** *Prolonging life and allowing death: infants.* Journal of Medical Ethics, 1995; 21: 339 – 344.

- **Hellmann, J.** *End of Life Decision-Making in the Neonatal Intensive Care Unit: Serving the Best Interests of the Newborn within a Family-Centred Care Framework:* In Paediatric Patient and Family-Centred Care Ethical and Legal Issues. LIME Vol 57, pp 221-244.

- **National Institute for health and Clinical Excellence (NICE) (2016).** *End of Life care for infants, children and young people with life-limiting conditions: planning and management.* NICE, London. Available at: https://www.nice.org.uk/guidance/ng61

- **Royal College of Paediatrics and Child Health (RCPCH) (2015).** *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice.* 3rd Edition. Available at: http://adc.bmj.com/content/100/Suppl_2/s

- **Willems et al (2014)**. *Infants' Best Interests in End of Life Care for Newborns.* Pediatrics 134:4

APPENDIX 5: Seeking Feedback from Families

Many parents who have experienced bereavement want to offer feedback to ensure lessons are learned and good practice is shared (London Clinical Networks 2017). Such feedback is invaluable in influencing care and how it is delivered. However, healthcare professionals are often concerned about when, and how best to seek such feedback from families. A survey was undertaken by the Stillbirth and Neonatal Death charity (SANDs, 2016). Of 437 respondents 95% felt it was appropriate for bereaved parents to be asked for feedback on their experiences and commented on how this could most appropriately be done. From this survey the Maternity Bereavement Experience Measure (MBEM) questionnaire was developed. Whilst this survey focussed on parents experience of maternity bereavement services much is applicable to neonatal and paediatric services, particularly those pertinent to this pathway. Therefore the MBEM, and accompanying letter, has been adapted (with the kind permission of the London Clinical Networks and SANDs) to gain feedback from parents of infants on this pathway.

Once approved for use printable copies of the letter and questionnaire will be available for download from the Rainbows website at:

www.rainbows.co.uk