RPPCN
Regional Paediatric
Palliative Care Network

Antenatal Palliative Care

Supporting you and your family every step of the way

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ANTENATAL PALLIATIVE CARE PATHWAY

Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
Address:	

Date pathway commenced: __ / __ / ____ By:

INFORMATION FOR FAMILIES

This pathway aims to ensure that the care and support you, your baby and your family receive at diagnosis and throughout your antenatal care informs you about choices, advises about benefits and risks of each option and assists you, as a family, to plan for any of the possible outcomes for you and your baby.

It is meant to ensure comprehensive communication across all the professionals you will meet, providing confidence that everyone knows what is important to you when it comes to the care of you and your baby. If at any point you don't understand any of the information you receive please ask someone to explain. We know that sometimes individual health requirements may vary from the hopes in this plan, in which case, members of the team will use their clinical judgement and help you review and adapt your care accordingly, with your knowledge and consent.

INFORMATION FOR PROFESSIONAL

(NB User Guidance is available for this document)

This pathway is applicable to everyone who has received an antenatal diagnosis of a potentially life limiting or life threatening condition for their baby. Examples of conditions that initiate the use of the pathway are listed on page 1 of the user guidance for professionals. The pathway encourages early referral to support services and facilitates discussion around parallel planning through the antenatal period. It also assists in defining arrangements around focus and place of care for birth and life and enables relationships to provide bereavement support. This joint approach to patient - centered care has the outcome based objectives of providing equity of comprehensive antenatal services, improving choice for family - centered care and ensuring access to follow up bereavement services when appropriate. Although this is a regional initiative, the pathway is intended to personalise the antenatal planning period in a way that maintains hope, and considers and plans for all possible outcomes.

This pathway is intended to be part of the patient held records and should be completed with patients under the principles of informed consent.

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DOCUMENTATION PATHWAY RECORDS

Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
Address:	

Signature Register *(Please complete if you are recording in this pathway)*

Name	Designation	Professional Registration Number	Initials	Full Signature

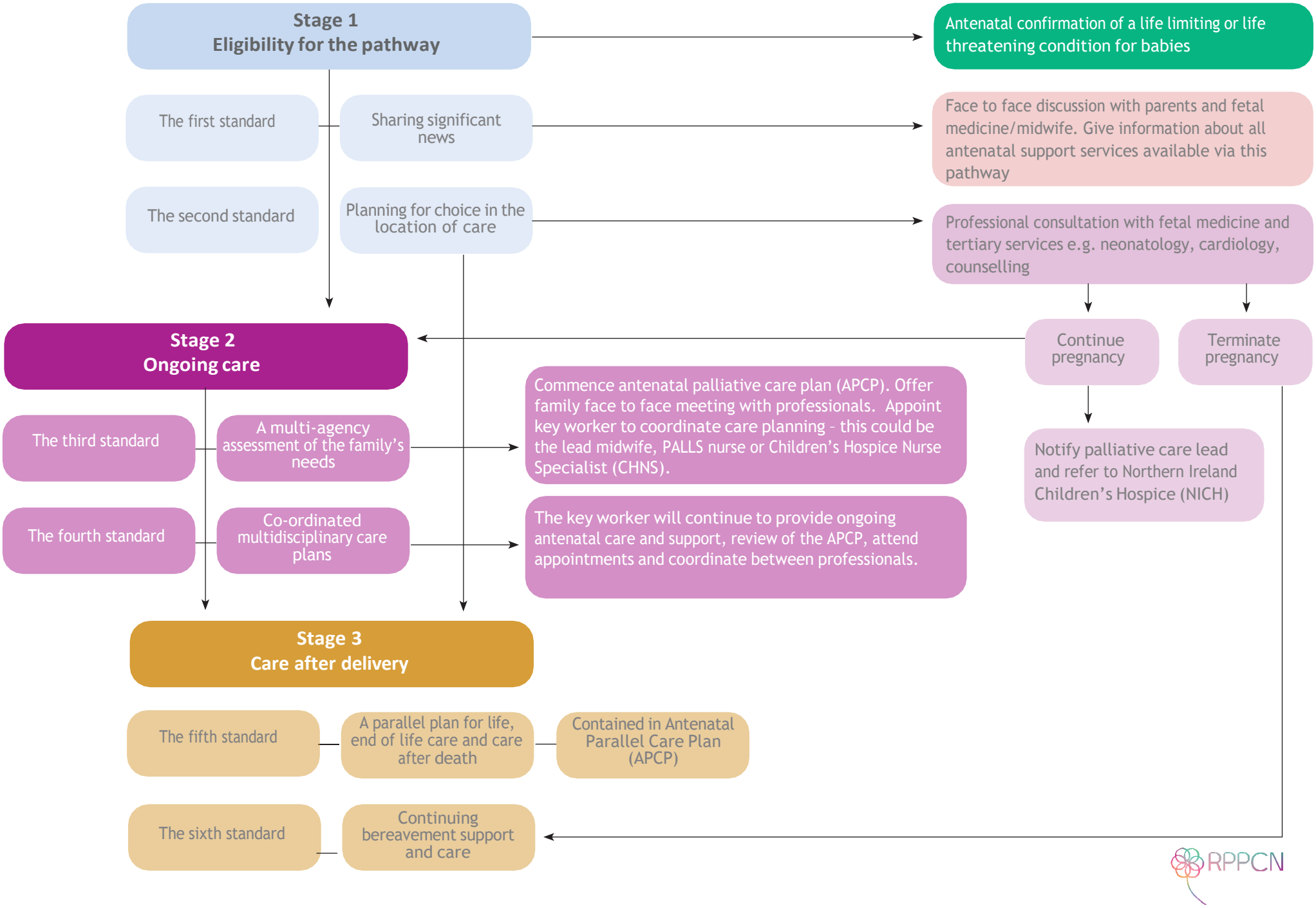
DOCUMENT SUMMARY & CONTENTS

SUMMARY

The overall pathway can be separated into sections. The colours of the sections match the flow chart and are also annotated here for ease of use.

The pages in the MDT section are for ongoing records and could be used as a master copy to ensure enough pages are available.

CONTENTS


Stage 1
Eligibility for the pathway
Antenatal confirmation of a life limiting or life threatening condition for babies
The first standard
Sharing significant news
Face to face discussion with parents and fetal medicine/midwife. Give information about all antenatal support services available via this pathway
The second standard
Planning for choice in the location of care
Professional consultation with fetal medicine and tertiary services e.g. neonatology, cardiology, counselling
Continue pregnancy
Terminate pregnancy
Stage 2
Ongoing care
Commence antenatal palliative care plan (APCP). Offer family face to face meeting with professionals. Appoint key worker to coordinate care planning - this could be the lead midwife, PALLS nurse or Children's Hospice Nurse Specialist (CHNS).
The third standard
A multi-agency assessment of the family's needs
Notify palliative care lead and refer to Northern Ireland Children's Hospice (NICH)
The fourth standard
Co-ordinated multidisciplinary care plans
The key worker will continue to provide ongoing antenatal care and support, review of the APCP, attend appointments and coordinate between professionals.
Stage 3
Care after delivery
The fifth standard
A parallel plan for life, end of life care and care after death
Contained in Antenatal Parallel Care Plan (APCP)
The sixth standard
Continuing bereavement support and care
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PATIENT DETAILS

Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
Address:	

This section is to be completed by Fetal Medicine consultant. Sometimes it will be when you get your scan with them or, it could be at your next appointment when they will discuss the scan result in detail. Fetal Medicine take detailed scans and measurements and these will be sent on to your lead obstetric consultant in separate notes.

Date and time of consultation

Family Details

Details of significant family members				
Siblings				
Baby's Gender		Male	Female	**Due Date:**
Diagnosis				

Any previous loss/ relevant medical history/any safeguarding or mental health issues?

Family's insight into assessed condition:

Awareness of diagnosis

- Parents ☐
- Siblings ☐
- Other significant family members ☐

Key worker can help in these discussions

Awareness of diagnosis

- Clinical Psychology ☐
- Bereavement Midwife ☐
- PALLS Nurse ☐
- Home Trust Palliative Medical Lead ☐
- Children's Hospice Nurse Specialist ☐ *(where PALLS not available)*

NOTE: Set out reason for non-referral should that occur:

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Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
Address:	

CONTACT DETAILS OF KEY PROFESSIONALS

This section should be completed and updated by the key worker. It will help you know who is leading in each part of the care for you and your baby, and is in the order in which you are most likely to meet people.

Appropriate Professional	Name	Contact Number *(Office & Out of Hours)*	At start of plan	On Discharge
Named Fetal Medicine Consultant				
Named Obstetric Consultant				
Key worker				
Paediatric Consultant who should notify the Palliative Care Consultant for home Trust				
Clinical Psychology				
PALLS or Children's Hospice Nurse Specialist for your Trust				
Bereavement Midwife				
Social Worker				
Local Unit				
Community Midwife				
General Practitioner				
Health Visitor				
Community Children's Nurse				
Interpreting Services				
Other				

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Surname:	
First Names:	
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Address:	

CONSULTATION
ANY MDT APPOINTMENT

Notes from any professionals can be recorded here, to provide an ongoing summary of care.

Date:	
Mother's Gestation:	
Who is present at consultation?	

Notes:

Any issues that are of concern to the family:

Plan for next appointment:

Sign:	Role:	Date:

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Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
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Any issues that are of concern to the family:

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Sign:	Role:	Date:

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Date of Birth:	
H&C No:	___/___/____
Address:	

PARALLEL BIRTH AND ONGOING CARE PLAN

This plan is to record your thoughts about what is important to you during the birth and care of you and baby after birth. It can be filled in with your key worker and other professionals as you make decisions. It is a guide to how you want things to go and can change at any time you wish it to.

LABOUR & DELIVERY CARE

Preferred place of delivery:	
Preferred mode of delivery:	

Who do you want with you in the delivery suite?

We do/do not want fetal monitoring during labour

If monitoring we prefer: Continuous ☐ Intermittent ☐ No Monitoring ☐ Undecided ☐

Preferred pain management during labour:

Other requests for the delivery suite environment:

What are the plans for resuscitation if needed?

Do you wish the placenta to go for placental analysis?	Yes ☐ No ☐

Other information

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CARE AFTER DELIVERY:

discussion and decisions that can apply if baby lives for a short time or if baby is stillborn.

When our baby is delivered we prefer to:

Briefly meet and touch/hold our baby but then have baby assessed by medical staff as soon as possible ☐

OR

Hold our baby as soon as possible and as much as possible. We wish to keep our baby with us in labour ward and delivery suite ☐

OR

We are undecided and will see how we feel at the time. ☐

While holding our baby we prefer our baby to be: Placed skin to skin ☐ Wrapped ☐

Family Time:

We would like a named family member to be present during the delivery if possible ☐	**Family member's name:**

We would like our family/friends to be able to join us in our room after delivery to spend time with and our baby ☐

We would like to bathe our baby ☐ **We would like to dress our baby** ☐

We would like help talking with our other child(ren) ☐

Special requests for sibling(s) and family members: Yes ☐ No ☐

Spiritual support:

Our faith tradition is	

We request that a ceremony (blessing, naming ceremony, baptism) be performed in accordance with our religious beliefs Yes ☐ No ☐

We wish a representative of our faith community to be contacted when our baby is born Yes ☐ No ☐

Special requests for spiritual support:

If our baby is not alive when born we would like to have the following keepsakes:

Photographs ☐ **ID Band** *(if available)* ☐ **Hand/Footprints** ☐ **Lock of hair** ☐

We do not wish to have any keepsakes ☐

I am/We are considering Organ Donation if possible Yes ☐ No ☐

Have you considered if you want your baby to go for post-mortem? Please go to page 15 of the pathway. http://www.hscboard.hscni.net/our-work/commissioning/perinatal-and-paediatric-pathology/

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ARRANGEMENTS FOR ONGOING CARE

We are not sure what the outcome will be for your baby in the early stages after delivery. In this part of the plan we think about what is important to baby, you and your family in the time after delivery. This will include your thinking about how and where you want to care for your baby.

What factors are important to you for your baby's care at this time? It could be things like support with care and feeding, access for family and friends or being close to home. You should think about all these things to help you decide if its best for you to go home, go back to, or remain in, your local hospital, consider staying in the Children's Hospice for a time or getting some help from Children's Hospice at Home.

Where would you like your baby and you to be cared for?

Would you like to consider transferring to another place of care after a period of time that you could decide on?

If so – professionals, please see transfer form at the end of this pathway.

Other information that is important in baby's care

Completed By:

Print Name:	**Job Title**
Signed:	**Date: _ _ / _ _ / _ _ _ _**

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CLINICAL END OF LIFE MANAGEMENT PLAN

An end of life plan is usually made when a baby is not expected to live for very long. Usually we don't actually know how long that will be, maybe a few hours, days or weeks. But our aim for life, however short, is optimum symptom management and comfort.

This section will be completed by the medical team to make sure everyone knows the goals for the treatment for your baby. This means we can make adjustments to care depending on how baby does while working within the parameters of these goals. This care plan is a guide and will be used to make sure your baby's care is planned to suit them best.

All care plans will be discussed with you, and should you need anything answered, or clarified, then please just ask one of the staff.

*Include specific details of management in the **'MANAGEMENT'** column, information within the **'POTENTIAL ISSUES'** column is for guidance only*

**Move this pathway to the baby's notes * unless there is a change of location of care then should accompany baby.*

Date:	Potential Issues	Management
	Feeding issues / vomiting Include current feeding regime and an alternative if vomiting **Options for alternative:** 1. Reduce feed volume 2. Increase time in between feeds **Consider:** 1. Anti-reflux medication	The goal of feeding: (Please circle) Nutrition Comfort Feeding note: Oral OGT NGT Type of Feed: _____ Current feed amount in mls/kg:_____ Frequency of feeding: _____ If symptoms associated with feeding arise please note the plan below.
	Increased secretions / noisy breathing If breathing becomes noisy and distressing consider: 1. Suction 2. Hyoscine patch	
	Temperature Control	Outline measures that are appropriate for temperature control

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CLINICAL END OF LIFE MANAGEMENT PLAN

Date:	Potential Issues	Management
	Pain Please be aware of the WHO analgesic ladder. Consider: sucrose; paracetamol; oral morphine.	Pain management plan should include measures for baseline pain and breakthrough pain once a baseline regime is established. Usual breakthrough dose is 1/6 th of total 24hour dose. Pain management plan: *If reduced absorption/ non absorption is suspected move to SC/ IV route.*
	Agitation and restlessness Consider simple management including position change, reassurance including skin to skin/cuddles. Consider using buccal midazolam or alternative routes i.e. intranasal	Outline measures that are appropriate for temperature control
	Seizure Activity Ensure buccal midazolam is prescribed for seizure activity. This should be prescribed **even if a child does not have a history of seizures, as this is a potential problem for end of life care.**	
	Constipation Introduce laxative therapy especially if Opiates are part of the pain management plan	
	Any other symptoms	
	Emergency Plan In the event of a sudden change contact:	

CARE AFTER DEATH

There are different options that you can choose and your key worker will be able to outline what the possibilities are to help you decide what is most suitable for you and your family. Initial plans are only made as a guide and you can change your mind at any time.

Discussions around care after death.

Options for care after death would be: at home: in Children's Hospice for support between death and funeral service.

What are your wishes for care after death for your baby?

APPENDIX I COMMONLY USED DRUGS

This is for guidance only, please refer to the source document before prescribing.

Drugs ref: APPM Master Formulary Edition 5th edition 2020 and matched with advice from RJMH SET neonatal pharmacy BRFC (online). appm.org.uk/guidelines-resources/appm-master-formulary

Other resources BNFc (online) bnfc.nice.org.uk

Name	Reason	Dose	Frequency	Method
Atropine sulphate	Antisecretory	20-40microgram/kg/dose	PRN - 2-3 times a day	Sub lingual
Hyoscine hydrobromide	Antisecretory antiemetic	250 micrograms Quarter of a 1 mg patch to skin do not cut the patch - use a dressing to occlude transdermal absorption from the non required area.	Every three days	Transdermal patch applied to hairless area of skin behind ear
Lactulose	Constipation	2.5 mls	Twice daily Adjusted according to response	Oral
Lansoprazole	Gastro-oesophageal reflux	0.2-0.3mg/kg but can go to range of 1 mg/kg	Once a day	Oral (melt)
Midazolam	Respiratory distress/dyspnoea Agitation	25 micrograms/kg 50 micrograms/kg 25 micrograms/kg 0.5 – 1.0 mg	Can be repeated after 15 minutes if required - repeat once and request review if symptoms not resolved. Repeat at hourly intervals as needed Over 24 hours Continuous infusion	Buccal Oral /NO /NG S/C or IV stat S/C or IV
Midazolam	Seizure	300micrograms/kg	Can be repeated once after 10 minutes	Buccal

APPENDIX I COMMONLY USED DRUGS

Drugs ref: APPM Master Formulary Edition 5th edition 2020 and matched with advice from RJMH SET neonatal pharmacy BRFC (online).
appm.org.uk/guidelines-resources/appm-master-formulary

Other resources BNFc (online) bnfc.nice.org.uk

Name	Reason	Dose	Frequency	Method
Morphine	Pain	25-50 microgram/kg	Every 6 - 8 hours	Oral
		120 microgram/kg/24 hours	Continuous Infusion	Intravenous OR SC
		10 - 16 % of total daily 24 hour dose	1-4 hourly as needed	Same route as background
	Respiratory distress	30-50% of the dose used for pain	PRN	Oral
Omeprazole	Gastro-oesophageal reflux	700mcg/kg increased if necessary after 7-14 days to A maximum 1.4mg/kg	Once a day	Oral
Paracetamol	Analgesia Pyrexia	**28 -32 weeks postmenstrual age** 15mg/kg as a single dose then 10-15mg/kg	PRN - 2-3 times a day Maximum dose 30mg/kg/24hours	Oral
		> 32 weeks postmenstrual age 15mg/kg as a single dose then 15mg/kg	PRN - 3-4 times a day Maximum dose 60mg/kg/24hours	Oral
Phenobarbital	Seizures	20mg/kg	Bolus	Slow intravenous injection
		Then: 2.5-5 mg/kg Dose and frequency adjusted according to response	Once or twice daily a day	Oral/slow intravenous injection
Sucrose solution 24%	Analgesia	32-36 weeks gestation: 0.5-1mL (regardless of weight) Term babies: 2mL (regardless of weight)	PRN - maximum 4 doses in 24hours	Oral

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TRANSFER FORM

Surname:	
First Names:	
Date of Birth:	
H&C No:	___/___/____
Address:	

This form will be completed by the team who are caring for your baby should you decide to move to another place of care. It is to make sure that the professional taking over baby's care know all the relevant details to continue care safely.

// Professionals - Please refer to contacts list to ensure all professionals are aware of the transfer //

Completed by Doctor

Current place of care:	

Please give a brief history this admission:

Most recent weight:	

Has there been an MDT including Key Worker prior to transfer? Yes ☐ No ☐
(If yes please incude minutes)

What is the focus of care for this transfer?

- **Step Down – continuing care to assist phased discharge** ☐
- **Step Up – to avoid hospital admission** ☐
- **End of Life Care** ☐

Based on recent history what pathway do you consider this child to be on?

Phase of illness:

Stable	Unstable	Deteriorating	End of Life
- Symptoms are adequately controlled by an established plan of care and - Further interventions have been planned and - Family situation is stable with no new issues	- New problem that was not anticipated and/or - A rapid increase in severity of a current issue and/or - Family circumstances change suddenly impacting on patient care	- Overall status is declining and - Experiences a gradual worsening of existing issues and/or - Experience a new but anticipated problem and/or - Family experience worsening distress that impacts on care	- Care is defined by focus of end phase of condition - Withdrawal of treatment

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Is there an Advanced Care Plan in place?	Yes ☐ No ☐
Is there an Emergency Care Plan in place?	Yes ☐ No ☐ *Please attach copies of plans*

Main areas of support to be addressed by this transfer: *Please Tick*

	Symptom Management
	Continuation of treatment with view to stabilising and discharge (step down)
	Family/social support

Outline details:

Record of discussion with parents around: *Please Tick*

	Phase of Illness
	Focus of Care
	Expectations of Transfer

What discussion have you had with parents? Please summarise their understanding.

Medications

Are all current medications continuing?	
Are they tolerated by current route?	

If changing around transfer, detail changes and planning discussions and decisions. *Ensure a copy of current medications is attached.*

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Medical handover

Is face to face review by receiving medic required?	Yes ☐	No ☐
Arrangements for medic to medic handover:		
Medical handover:		

Nutrition and hydration

Is a dietician currently involved?	Yes ☐	No ☐
Name		
Contact Details		
Please outline what level of hydration and nutrition are being tolerated at present:		
What is the focus of feeding?	Nutrition and growth ☐	Comfort ☐
What are the immediate plans for feeding?		
If a proton pump inhibitor prescribed? If so what is the Consultant's advice for feeding if PH is above 5.5?		

Please ensure a written feeding plan is available prior to transfer

Breathing

Pain Management

Family Support

Is there current social work input?	Yes ☐	No ☐	
Reason for that input:			
Is the child on the Child Protection Register?	Yes	No	Details
Are there contact orders in place?	Yes	No	Details
Any change in family dynamic or make up?			
How are the family coping?			

Please ensure a written feeding plan is available prior to transfer

Additional resources required before transfer :
Equipment:
Medication:
Specific training:

Make all professionals aware of transfer	
Date of next planned MDT review:	
Information collected by:	
With:	

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Antenatal Palliative Care

USER GUIDE

for MDT Professionals

BACKGROUND INFORMATION

Antenatal and perinatal palliative care is an integrated multidisciplinary team approach supporting holistic care to families anticipating the death or potential death of their baby.

The NI DOH Strategy for Palliative and End of Life Care for infants, Children and Young People 2016 -26 states in objective one that, in the case of pre-birth diagnosis, information and advice on perinatal hospice care and palliative care and support for parents are to be provided.

It is recognised that in this situation each family is on a journey with their baby from diagnosis to birth and the aim of this pathway is to standardise best practice; to provide the highest quality family-centered care ensuring that families are aware of all the options for support through this time. (North West Perinatal / Neonatal Palliative Care Guideline 2016).

This pathway is informed by the Thames Valley Perinatal pathway and adapted from the Together for Short Lives perinatal palliative care framework. It follows the standards set out in that framework and this guidance is structured to relate to each standard for ease of reading.

The focus of language in the pathway is around the antenatal care period - taking the opportunity of this time to assist families in deciding what is important for them and for their baby. Care planning for perinatal and ongoing life is a central part of the antenatal care, so this pathway should not be interpreted as applying to antenatal care only. Rather, it is intended for all professionals who will interact with a family on their journey during the antenatal phase to facilitate advanced planning.

We envisage that the pathway will be held by the family in the patient held record and can be added to by any professional in the MDT as they consult.

SUMMARY GUIDANCE

This guidance gives background to the various stages of the pathway and is supported by an educational video.

However - below is a summary of the essentials:

The pathway should be used as an appendix to the green patient held maternity record and added as needed

The section in the pathway for professional's names is intended for those who are seeing the family because of the diagnosis and not as part of the routine antenatal care. If you have entered name and professional details to the green notes there is no need to duplicate.

The consultation section is intended to assist easy access to a history for MDT discussions from paediatrics etc. Any routine antenatal screening should be recorded in the usual section in the green notes.

The list of professionals who can work as key workers are available to assist you - please refer to them as they can take on the planning work with the family.

This pathway assists advanced care planning so that all professionals can respond with a co-ordinated approach.

STAGE ONE
ELIGIBILITY FOR THE PATHWAY

Confirming eligibility

Women and families who have had an antenatal diagnosis of a confirmed or potential life-limiting/ life threatening condition and who are continuing their pregnancy would be considered eligible for Antenatal Palliative Care.

Examples of life- limiting conditions include but are not limited to:

- Anencephaly.
- Holoprosencephaly.
- Hydrancephaly.
- Severe skeletal dysplasia.
- Bilateral renal agenesis.
- Trisomy 13,18.
- Severe Osteogenesis Imperfecta.

Life- threatening conditions

Prognosis may not always be clear at time of diagnosis, however there is a significant chance of death in utero, in the newborn period, or early infancy.

E*xamples of life threatening conditions may include:*

- Severe Hydrocephalus.
- Severe congenital condition .
- Hydrops fetalis.
- Severe multi cystic dysplastic kidneys and oligohydramnios.

It is also relevant to consider children who may have a condition that has potential to limit their life beyond infancy but into childhood.

Assessment at birth to finalise treatment plans and ceilings of care will be appropriate in each situation.

1ST STANDARD
SHARING SIGNIFICANT NEWS

This standard is supported by objective 12 of the NI DOH EOL strategy which states that "the relevant professions should communicate in a clear and honest manner so that families understand their baby's condition and the implications of various options." This enables families to contribute to a flexible parallel plan for their baby. Diagnosis may be confirmed by the fetal medicine team in Royal Jubilee Maternity Hospital, or by the local fetal medicine department e.g. the South Eastern Trust.

At this very stressful time and to assist with follow up conversations, the pathway would advise the MDT to appoint a key worker for the family.

The key worker at this stage would:

- Promote collaborative working acting as a conduit for professionals from diagnosis
- Provide emotional support for parents around the breaking of bad news
- Be a point of contact for follow up information
- Help parents share bad news

Possible key workers are suggested as:

Bereavement Midwife (available in all Trusts) of various options. This enables families to contribute to a flexible parallel plan for their baby. Diagnosis may be confirmed	Northern Trust *LesleyAnn.Kennedy@northerntrust.hscni.net* Western Trust *Melissa.crockett@westerntrust.hscni.net* Belfast Trust *Barbara.Gergett@belfasttrust.hscni.net* Southern Trust *Oonagh.king@southerntrust.hscni.net* *Shivaun.mckinley@southerntrust.hscni.net* South Eastern Trust *Jacqueline.dorrian@setrust.hscni.net*
Palliative and Life Limited Family Support Nurse Belfast Trust and Northern Ireland Children's Hospice (NICH)	Rosie Hanna *07736 270 724*
Children's Hospice Antenatal Service (Available in all Trusts) Children's Hospice Nurse Specialists can take on the key worker role and support the family through this pathway and into bereavement with two years bereavement support where wanted.	Contact Hospice Hub *07526203819*

2ND STANDARD PLANNING FOR CHOICE IN THE LOCATION OF CARE

This standard is best met with a face to face discussion with the fetal medicine team and the family in the regional centre or local care setting. Fetal medicine staff will liaise with other professionals in services to begin to plan appropriate care. At this time it is important to consider how the family will be supported through this period - so if a key worker has not been appointed by this stage, it should be done here.

Providing a key worker has the potential to reduce workload for busy professionals as they can rely on ongoing support and information for the family as well as onward referral to appropriate services being attended to.

Points for practice

• Provide written information that summaries the conversation and contact details for ongoing support

• If the family decide to continue the pregnancy, notification should be made to their local trust Palliative Care Lead – this is for the purposes of data collection and email notification is acceptable.

Belfast Trust	Mairead McGinn	mairead.mcginn@belfasttrust.hscni.net
SE Trust	Karen Courtenay	karen.courtenay@setrust.hscni.net
Southern Trust	David Graham	david.graham@southerntrust.hscni.net
Western Trust	Joe Clarke	joe.clarke@westerntrust.hscni.net
Northern Trust	Ruth Sutherland	ruth.sutherland@northerntrust.hscni.net
Regional Consultant PPC	Marian Williams	marian.williams@belfasttrust.hscni.net

• If a family chooses not to continue with pregnancy bereavement support should be signposted by the bereavement midwife in their local trust.

• At this point some families will be referred back to local trust areas. The pathway will detail care appropriate in their preferred location.

STAGE TWO
ONGOING CARE

Ongoing care should monitor the pregnancy and help families access the full range of care and support services that may have potential benefit to facilitate their choices. Ensuring that there is co-ordination of services is key to the ongoing process of care, assisting with the development of therapeutic relationships and achieving goals of family-centered care.

3RD STANDARD
MULTI-AGENCY ASSESSMENT OF FAMILY NEEDS

Each family should have a multi-agency assessment as soon as possible after diagnosis. This is supported by objectives 4,5 and 6 of the NI Department of Health 2016-2026. Parents should be involved in the assessment as they are an integral part of all discussions and decision making.

The key-worker role at this stage should be focused on:

- Comprehensive and timely communication across professionals including onward referral.
- To assist in completion and review of the antenatal pathway and perinatal advanced care plan.
- Psychological support for parents and siblings.
- Referral to Clinical Psychology where required.
- To offer support to attend appointments.
- If a family chooses not to continue with pregnancy bereavement support they should be signposted by the bereavement midwife in their local trust.
- At this point some families will be referred back to local trust areas. The pathway will detail care appropriate in their preferred location.

4TH STANDARD
CO-ORDINATED MULTIDISCIPLINARY CARE PLANS

Flexible parallel care planning is essential in providing responsive care to the family and the baby. NICE (2016) outlines parallel planning as a method that "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.

"The antenatal pathway encompasses all aspects of parallel planning by including care throughout pregnancy, family wishes for the baby's birth and end of life care, decisions about resuscitation, symptom management plan and emergency care plan."

STAGE TWO
ONGOING CARE

4TH STANDARD
CO-ORDINATED MULTIDISCIPLINARY CARE PLANS

(CONTINUED)

Points for practice

- Family-centered care, including psychological, spiritual and social support can be provided by trust professionals and Northern Ireland Children's Hospice antenatal care service.
- Care should reflect the wishes of the family and best interests of the baby.
- Palliative care may be appropriate even if full resuscitation and active management is considered in the newborn period.
- Ensure involvement of all relevant professionals in multi-disciplinary meetings.
- Families should be given the choice and encouraged to attend MDT meetings.

STAGE THREE
CARE AFTER DELIVERY

The baby's best interests, quality of life and comfort are the main considerations following delivery; along with support for the family, including siblings and grandparents.

5TH STANDARD
END OF LIFE CARE PLAN

Care for the baby at end of life should be discussed as part of the antenatal pathway advanced care planning.

Parents should be given information on options for preferred place of care including hospital, home or Northern Ireland Children's Hospice. These discussions can be loosely planned in the antenatal period, but there must be a recognition that baby's condition may not be as expected when delivered.

Depending on the clinical situation and the level of support required, the lead clinician and family key worker should discuss and decide with the parents where the baby will be cared for, explain what is likely to happen and take their wishes into account as far as possible. Once location of care is decided appropriate communication is assisted by the transfer form in the pathway.

If a baby is being transferred home or to the Northern Ireland Children's Hospice, the mother's health must also be considered and planned for. In the case of attending Northern Ireland Children's Hospice, the local community midwifery service at Whiteabbey will provide ongoing care.

STAGE THREE
CARE AFTER DELIVERY

6TH STANDARD
CONTINUING BEREAVEMENT SUPPORT AND CARE

Please note that Northern Ireland Children's Hospice can provide up to two years bereavement care and continued support for families and siblings is available in a timely way. Every family is unique, therefore flexibility of provision is necessary to meet individual need.

Points for practice

- Families should be given the option of a follow up appointment with their consultant to discuss any issues which might impact on their bereavement journey, or future pregnancies.
- Where families choose not to engage with bereavement support signposting literature should be provided in case of future need.
- Bereavement literature should be available for all families.

RELATED DOCUMENTS

Together for Short Lives: Perinatal Pathway for Babies with Palliative Care Needs: www.togetherforshortlives.org.uk/perinatal pathway

British Association of Perinatal Medicine: Palliative care (supportive and end of life care) A framework for clinical practice in Perinatal medicine (2020)

Thames Valley and Wessex Neonatal Operational Delivery Network July 2017

Basic symptom control for paediatric palliative care version 9.5. https://www.togetherforshortlives.org.uk/wp-content/uploads/2017/12/ProRes-Symptom-Control-Manual-with-4th-edition-formulary-2017.pdf

Department of Health NI - Strategy for Palliative and End of Life Care for infants, children and young people 2016- 2026

https://www.health-ni.gov.uk/sites/default/files/publications/health/paediatric-strategy-palliative-end-of-life-care.PDF