Perinatal palliative care and the parallel planning process

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Life-altering changes in expectations

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Background - UK Stats

- Over 80,000 babies admitted to NNUs each year
- Around 2000 neonatal deaths due to causes likely to require palliative care
  - 98% of neonatal deaths occur in an NICU
  - few are supported to die at home or in hospice
- The prevalence of LLC in was highest in children under 1 year and then decreased through the age bands
- Palliative Care is the holistic care of the baby and family from the point of recognition through life and bereavement to maintain quality of life and support

Perinatal palliative care

ANTENATAL BIRTH POSTNATAL

Severe congenital abnormalities:
- Chromosomal
- Cardiac
- Central nervous system

Extreme prematurity
Hypoxic ischaemic event

Overwhelming illness:
- Sepsis
- Persistent pulmonary hypertension from a transitional circulation

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Publications

- **RCPCH**: Witholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (2004)
- **ACT/Together for short lives**: A Neonatal Pathway for Babies with Palliative Care Needs (2009)
- **GMC**: Treatment and Care Towards the End of Life: good practice in decision-making (2010)
- **BAPM**: Palliative care framework for clinical practice in Perinatal medicine (2010)
- **Bliss**: Quality Improvement Programme in Palliative Care (2011)
- **RCPCH**: Practical guidance for the management of palliative care on neonatal units (2014)
- **NICE**: Guidelines for Paediatric Palliative care. (2016)
- **Together for Short Lives**: Perinatal care pathway. (2017)

Goals of Perinatal Palliative Care

- Support for family after diagnosis of a fetal condition which may mean that their baby may not live for very long

- Multi-disciplinary Team
  - Diagnosis and prognosis
  - Develop a sensitive birth plan
  - Preparation of entire family for birth, death and bereavement
  - Parallel planning: maintain realistic hope while making plans for each eventuality: Plan A, Plan B, Plan C

- MDT discussion: family, obstetric team, midwives neonatologist, palliative care team/hospices

DOCUMENTATION

Our role

- Determine diagnosis and make best estimate of prognosis
- Determine all relevant medically appropriate, legally and ethically acceptable options
- Elicit family philosophy, overall goals
- Assist families to consider the choices
- Ensure a clear plan and explanation of what will happen at delivery and first few days and address physical, social, emotional, spiritual support

Parallel planning

- Maintain realistic hope
- Provide intensive pain & symptom management
- Describe clinical condition as a whole
- Evaluate benefits vs. burdens of treatments
- Affirm parents' efforts and love
- Staff empowerment

Challenges of perinatal palliative care

- Diagnostic uncertainty and speed of deterioration
  - time together can be short
  - Baby's condition may change suddenly
- There may be multiple births
- The mother may be very unwell
- Partners have significant needs
- Different healthcare teams involved
- New parents may be tired, stressed and emotional and the mother may also need postnatal care

Barriers to Perinatal Palliative Care

- Societal expectation that babies don't die
- Continued confusion that PC = hospice = death
- Death = failure to health care professionals
- Inadequate PC training & experience of providers
- Focus on "life-prolonging" interventions
- Paucity of evidence base

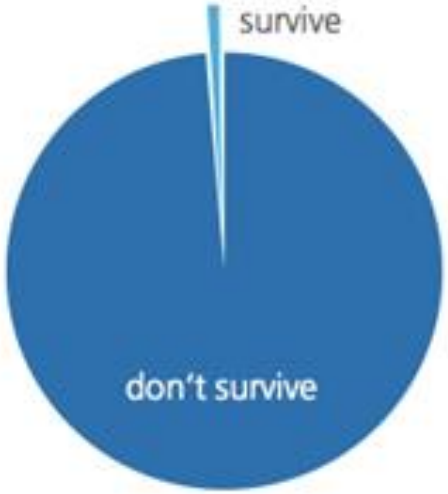
Strategies to Overcome Barriers

- Staff training
- Close MDT working and documentation
- Children's hospices
- Promote open discussions as part of the environment of care
- Parent education
- Model programs – leadership
- National awareness raising

Improvements in parallel planning

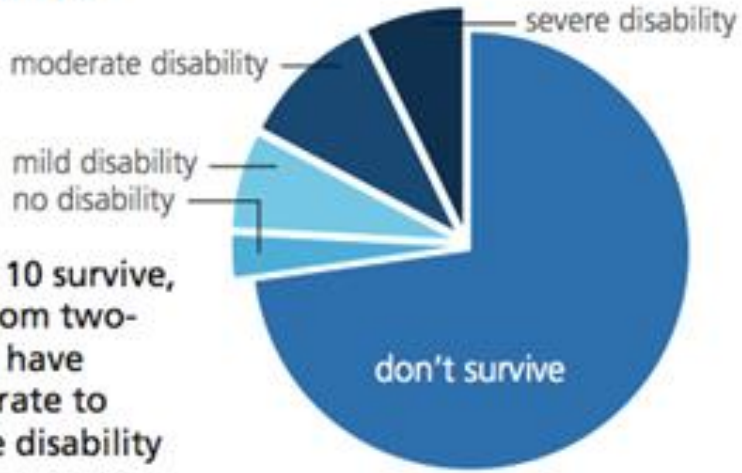
- Register birth early
- Early blessing/religious ceremony
- ‘Journey box’
- Diary
- Hand and foot prints at admission
- Don’t be afraid to discuss potential outcomes

22 weeks



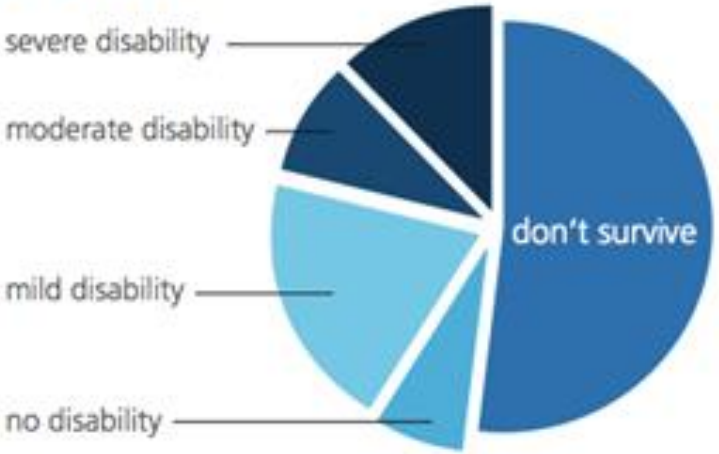
Only 1 in 100 babies survive with likely severe disability

23 weeks



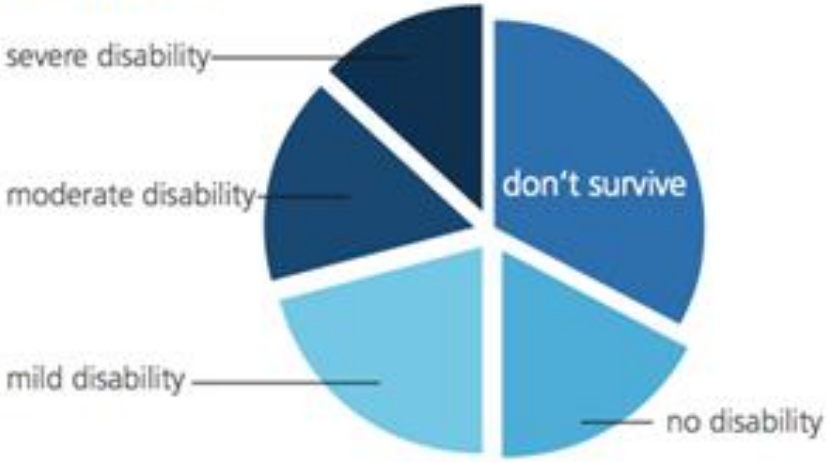
2-3 in 10 survive, of whom two-thirds have moderate to severe disability

24 weeks



4-5 in 10 survive, of whom half have moderate to severe disability

25 weeks



6-7 in 10 survive, of whom 4 in 10 have moderate to severe disability

North West Neonatal ODN and Fetal Medicine Network Antenatal Congenital Anomaly MDT communication, planning and documentation form for babies with potentially short lives

Insert addressograph

Mothers Name .....

Home Address .....

GP name and address .....

Current EDD .....

Place of Booking .....

Fathers Name .....

Has the baby been named? Y/N

Baby's Name .....

THIS DOCUMENT IS TO BE:

- *Commenced by the fetal medicine team along with a neonatal/paediatric consultant AS SOON AS a diagnosis has been discussed with parents and a decision made to continue the pregnancy*
- *Kept in the maternal hand held notes*
- *Be reviewed at each appointment*
- *Distributed to the following:*

Who should be sent a copy of this document?	1. Neonatal Antenatal Alert file 2. Mother's GP 3. 4. 5.

Initial MDT (to take place as soon as possible after definite diagnosis): Section 1-5		
Section 1 – Diagnosis **To be completed by FMU lead clinician**		
Details of diagnosis		
USS (confirmed by Fetal Medicine Consultant)		
CVS/Amniocentesis		
MRI		
Fetal Echocardiography		
Other prenatal investigations		
Section 2 – Multi Disciplinary Team (MDT) meeting		
Location of meeting		
Date of MDT meeting		
Persons present *Please write names*	Fetal medicine Consultant/Obstetrician	Others: (e.g. general paediatrician surgeon, cardiologist, nephrologist)
	Consultant Neonatologist	

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Section 3 – MDT Discussion (key points)
Place of delivery
Timing of delivery
Mode of delivery
Monitoring in labour
Persons to be present at delivery
Specific care to be provided at delivery (including scope/extent of planned resuscitation, Action/plan if resuscitation is not successful in delivery room, Comfort care measures)
Early neonatal management plan and location where care will be delivery (including stay on delivery suite or transfer to NICU, possible treatment, early transfer to community setting: hospice or home care, if baby is showing signs of surviving for days, weeks, or months)
What are the family's priorities if the baby's life is likely to be short (hours/days)?
Discussion of post-mortem: has this been offered (**specify** by whom and when expected)
Has organ or tissue donation been considered/discussed with local Specialist Nurse for Organ Donation and offered if appropriate?

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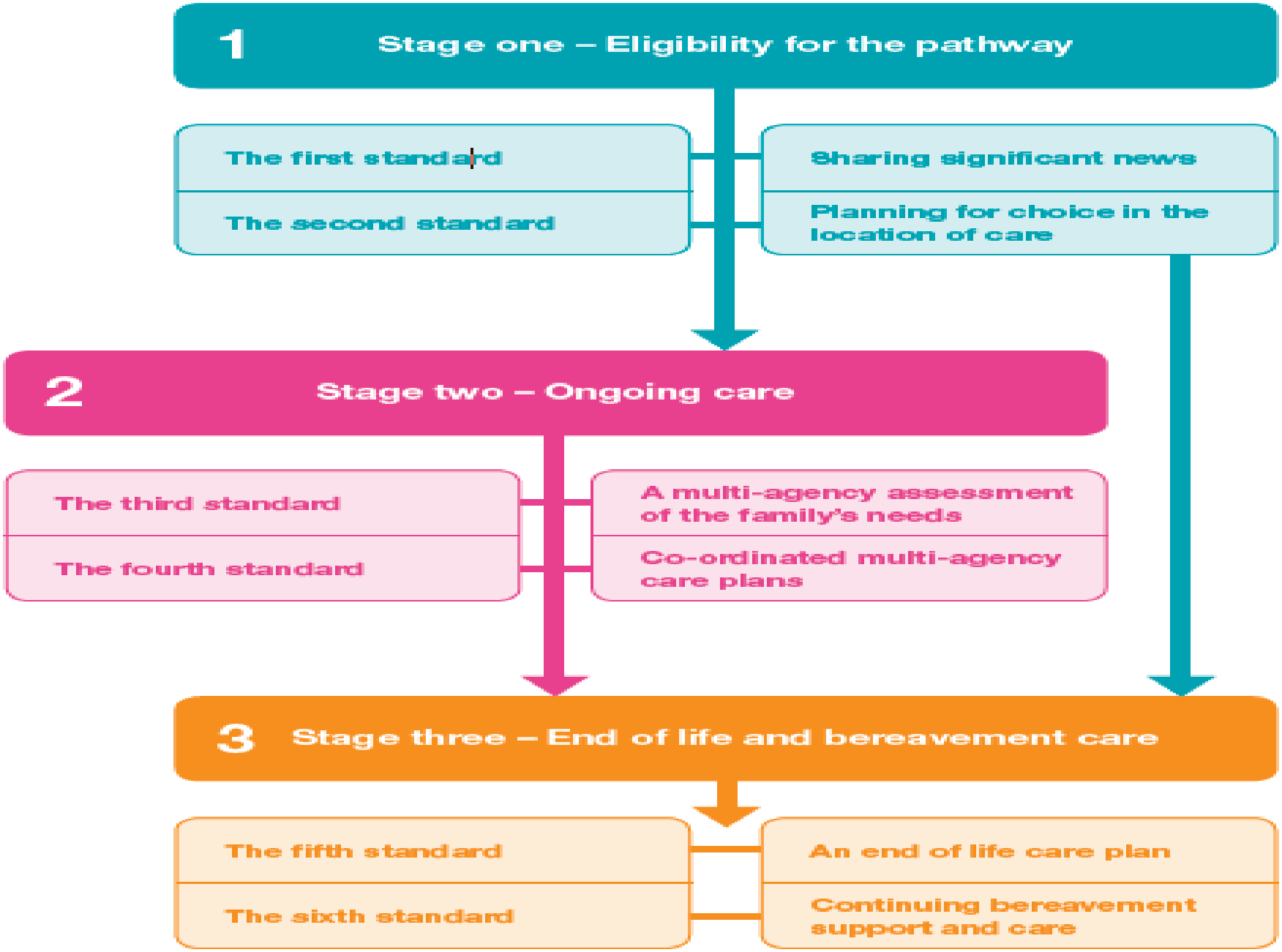
Section 5: Pre-Delivery Review MDT Meeting (usually 2 weeks before planned delivery date)		
Persons Present at MDT		
Confirmed diagnosis		
Delivery plan CONSIDER place of birth: if intensive care neonatal services are not essential at birth, could the baby be delivered closer to home?	Planned date	
	Planned place	
	Planned mode	
	Monitoring?	
Is the original plan still valid?	YES/NO	
Has anything changed since initial review?	YES/NO *If yes document below*	
Specific planning for immediate postnatal care reviewed: Has the following been discussed and documented? • Monitoring in labour • Scope/extent of planned resuscitation • Possible treatment • Action/plan if resuscitation is not successful in delivery room • Comfort care measures • Place of care • Options for hospice or home care if baby is showing signs of surviving for days, weeks, or months		
What are the family's priorities if the baby's life is likely to be short (hours/days)? e.g. memory making, photographs, family to visit, naming ceremony		
Are there any specific spiritual or cultural needs at the time of infant's birth and/or death?		


1
Stage one – Eligibility for the pathway
The first standard
The second standard
Sharing significant news
Planning for choice in the location of care
2
Stage two – Ongoing care
The third standard
The fourth standard
A multi-agency assessment of the family's needs
Co-ordinated multi-agency care plans
3
Stage three – End of life and bereavement care
The fifth standard
The sixth standard
An end of life care plan
Continuing bereavement support and care

Anomalies on 12-20 week scan		No antenatal anomalies detected
Genetic testing consented to: Diagnosis confirmed Trisomy 18	**Genetic testing NOT consented to**	**Dysmorphic features detected at birth**
THE FIRST STANDARD - sharing of significant news		
THE SECOND STANDARD planning for choice in the location of care: • **Confirm place, timing, mode of delivery, monitoring in labour** • **Care to be provided at delivery** • **Place baby is to be cared for after delivery** • **Options for hospice/home care** • **Symptom management plan** • **What are the family's priorities: memory making, family to visit, naming ceremony** • **Specific spiritual or cultural needs at the time of infant's birth and/or death?**	**Antenatal parallel planning discussion:** • **Could be 'fixable'** • **Could be life limiting** • **Could die at birth** **Need a diagnosis to inform prognosis**	**Postnatal parallel planning discussion:** • **Could be 'fixable'** • **Could be life limiting** **Need a diagnosis to inform prognosis**
	Diagnosis confirmed postnatally on at Day 3 of life of Trisomy 18 **THE FIRST STANDARD**: sharing of significant news **Discussions about de-escalation of life prolonging interventions.** **Introduce idea of palliative care,** **Involve children's hospice, palliative care team,** **Discuss moving out of hospital** **SECOND STANDARD** - Planning for choice in the location of care	
THIRD STANDARD - A multi-agency assessment of the family's needs **FOURTH STANDARD** - Co-ordinated multi-agency care plans		**Needs analysis/ Transport/Equipment** **Advanced care plan/Anticipatory prescribing**
THE FIFTH STANDARD - An end of life care plan		
THE SIXTH STANDARD - Continuing bereavement support and care		

Take home message