Neonatal Complex and Palliative Care

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2018 Training Workshops
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In 2010—the prevalence of LLCs in children in England was double the previously reported estimates and had increased in all areas (Fraser et al. Rising National Prevalence of Life-Limiting Conditions in Children in England Pediatrics 2012;129: E923-E929)
Why is neonatal palliative care different?

- New member of the emerging family
- New parents who are learning to be parents
- High levels of prognostic uncertainty
- Ongoing technological developments
- Emerging specialty
What’s new?

- Increased survival rate
- Media interest
- Research
- Neonatal organ donation
- Minimally invasive post mortems
- International Children’s Palliative Care Network (ICPCN)
- European Association for Palliative Care-Paediatric Taskforce

- New publications
- University courses
- Online training
- Dedicated nursing roles
- Medical training
- Special editions journals
- Recognition in it’s own right and specialty
Charlie Gard: Parents ask judge to 'give him a chance'

My 16 days of living with my DEAD baby: Mother spends over two weeks caring for deceased month-old infant after hospice provides her with refrigerated cot

- Charlotte Szakacs, 21, from York gave birth to first child in December
- Evlyn was born with rare chromosomal abnormality and died at four weeks
- Stayed in refrigerated 'cuddle cot' at hospice so parents could take her for walks
- Parents then took her home for four days before funeral

The Telegraph

'I kept my daughter in her bed for 11 days after she died'

Coma mum: I held my son three weeks after he died

Twins born at 23 weeks are 'little miracles'
• What does the term palliative care mean to you?

• Which babies would be considered as having palliative care needs?
Perinatal Palliative Care

‘Perinatal/neonatal palliative care is the planning and provision of supportive care during life and end of life care following multidisciplinary agreement on eligibility for a fetus, neonate or infant and their family’

(British Association for Perinatal Medicine 2010)
Criteria

1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival
2. An antenatal or postnatal diagnosis of a condition which causes a high risk of significant morbidity or death
3. Birth at the margins of viability, where intensive support has been deemed inappropriate
4. Postnatal clinical condition with a high risk of impairment of quality of life and the baby is receiving or may require life support
5. Postnatal conditions which result in the baby experiencing ‘unbearable suffering’ (BAPM 2010)
Consider

• Antenatal diagnosis
• Extreme prematurity
• Birth trauma
• Genetic conditions which are life limiting
• Surgical conditions
• Acute medical conditions
Neonatal Palliative Care

- Parallel Planning
- Early referral
- Timely discharge transfer
- Coordinate MDT
- Advance Care Planning
- Flexibility
- Key worker
- Choices

Baby Parents Family

Chelsea andViews
Specific needs of families

- New parents
- Mother’s health
- Father
- Other children
- Multiple births
- New life alongside possible death
- Time
- Financial
- Emotional
- Memories for a lifetime
Advance Care Planning
Discharge
Parallel/Dual Planning

- Plan for home with support
- What does support at home mean for that family?
- Is there an opportunity to meet the team in the community before go home?
- If there is a hospice service-introduce the team before the baby born if there is time
The baby’s needs should be assessed and a plan of care should be discussed and developed with the family, wherever that may be.
Care after death

- Death certificate
- Registering death
- Organ donation
- Post Mortem
- Burial
- Funeral
- Continuing support & contact
• Haven House-Woodford Green
• Richard House-Beckton
• Demelza-Kent
Donation of breast milk after death of a baby

- Information
- Choice
- Meaningful
- Care for the mother
Developed by parents for parents
Dr Faith Barker and Louise Howarth – London NTS
Neonatal Palliative Care Transfer Service Development
• NICE quality standard 13
  • “People approaching end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and is delivered by people who are aware of the person’s medical condition, care plan and preferences.”

• NHS Commissioning Service Specification E08*
  • Sometimes the circumstances of transfer are complex and it is not clear which is the responsible transport team. When this happens there should be clear decisions made in the best interests of the patient.
  • Ensuring that parents whose babies are unlikely to survive or have life limiting conditions receive sensitive support and care which follows a recognised Palliative Care Pathway. (E08/S/a)

• NTS context – transferring babies from appropriate place for on going care
  • **Population:** Neonates are defined as those babies who are generally (but not exclusively) less than 44 weeks post menstrual age. However for neonatal Transport Services the definition is expanded to any baby being transferred into or out of a neonatal unit of any level.”

• Stakeholders – CCG, NTS, London NICU/HDU/LNU, Hospices, Families
NTS Palliative Care Survey

- Sent to every unit in London responsible for providing Neonatal Care
- Special Care Baby Unit (Level 1) n=4
- Local Neonatal Unit (Level 2) n=14
- Neonatal Intensive Care Unit (level 3) n=8
- Did not include GOSH, Royal Brompton or Evelina (Specialist Units)
NTS Palliative Care Survey Results

- Every unit responded
- ~88% respondents would find a 48hr referral period acceptable
- Most felt assistance with coordination of transfer planning would be helpful
- Most would involve the palliative care team prior to making a referral
- About one third of respondents had not made a palliative care referral
  - There is enthusiasm and a desire for this service
  - Most feel a planned and coordinated transfer is ideal
  - Assistance with coordination and planning is welcome
  - To reach the standards of care required ongoing education is vital
NTS Palliative Care Service progress

- We are in process of introducing this to the team
- We will roll out via the ODN and Unit collaboration by the New Year – via lead Clinician, Nurse and Palliative Care teams
- We will debrief after each transfer – units, transfer and hospice/place of care teams
Neonatal Organ Donation

The diagnosis of death by neurological criteria in infants less than two months old

April 2015

Updated recommendations

Implications for practice
Publicity about UK's youngest organ donor prompted millions to think and talk about organ donation

Monday, 28 Sep 2015

More than 4 million parents considered whether they would donate their children's organs after learning of Teddy Houlton, the UK's youngest organ donor.

Teddy, who lived for just 100 minutes, successfully donated his kidneys to an adult.

His parents, Mike Houlton and Jess Evans, will this week receive a Special Recognition Award at the Daily Mirror's Pride of Britain Awards.

In a survey, published to coincide with the awards, 37% of UK adults who recall news coverage of Teddy's donation – an estimated 4.3 million adults - said it made them think whether they would want their own children to be organ donors."

Teddy's "extraordinary gift" prompted parents to reconsider donation of their own organs when they die and to talk about organ donation (INFO 1299/1)

Organ Donation and Babies With Congenital Life-Limiting Conditions

Introduction

There are a small but increasing number of enquiries from clinicians and parents about the possibility of organ donation from small babies with anencephaly and other congenital life-limiting conditions.

NHSBT wishes to be supportive of the parent's wishes for their baby to be an organ donor. However, it is also necessary to be realistic in managing expectations.

Therefore, parents and referring clinicians should be aware that, at present,

1. The only organs that may be transplanted are the kidneys: these will be used en bloc and for a small adult.

2. Hepatocytes may be prepared from donated liver and used for transplantation.

3. Heart valves may be retrieved if the baby weighs more than 2.5kg.
• 30 SNODS London
• Refer early to discuss suitability
• Key criteria-Term and 2.5kg
• Assessed over the telephone or onsite assessment
• Triggers-Plan to withdraw life-sustaining treatment or Signs of Brain Stem Death
Children’s Understanding of Death at Different Ages

- **Children under 2 years old**
  - Long before they can talk, babies are likely to need to explore and change the way they are perceived or treated by the caregivers who are responsible for them. Do they become a baby, a toy, or a part of the family?
  - Toddlers may show a lack of understanding of death when they have a dead bird or a dead fish. They may also not seem to understand the implications of this, such as the dead bird's doing anything or not being able to eat or drink.

- **Children from 2 to 8 years old**
  - To think provides help in explaining what is happening. Children at this stage see death as a temporary experience and are not yet ready to accept the idea of death. They believe that the person who died may come back or may have gone to heaven.
  - For example, they may believe that the person who died is alive again.
  - They may not understand the concept of death as permanent. They insist on understanding what it is that happens when a child dies.

- **Children of primary school age**
  - Begin to develop an understanding that death is permanent and final. They may be fascinated by the physical processes of death or the rituals surrounding it.
  - They may see death as a process that makes them more concrete or of a better life. They may see death as a process that makes them more concrete or of a better life. They may see death as a process that makes them more concrete or of a better life.

When your baby dies – a particular sort of grief

When a baby dies, the parents are expected to feel a grief that has no comparator, a particular sort of grief. The news that there has been a miscarriage or stillbirth is often unexpected and life-changing. You may feel overwhelmed and unsure of what to do.

When a baby lives for a short time, or dies before birth due to a misdiagnosis or an error in the decision to end or interrupt pregnancy, you may feel guilty about the loss.

When your grief is intense, you want comfort. You may feel that you are not ready to move on, that you need to be stopped or that you need to be told what to do.

When you feel alone, you may feel that you are not ready to move on, that you need to be stopped or that you need to be told what to do.

When you feel that you are not ready to move on, that you need to be stopped or that you need to be told what to do.

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Bliss

- Family care nurses
- Bliss volunteers
- Buddy
- Support for families & staff
- Resources
Together for Short Lives

• Support
• Resources
• Post Mortem Consent Forms
• Support for families & staff
• Reports & recommendations
TAMBA

• Helping Hands
• Befriender
The Family Fund

Guidelines on Family Fund grants for families of premature babies

Family Fund can consider applications on behalf of a premature baby where the following circumstances apply:

- A premature baby is dependent on technology to feed, breathe or to support life (i.e. without this they would be at risk of serious harm / death).
- A premature baby has an underlying medical condition that will need (or has received) surgical intervention – for example, heart surgery, repair to a diaphragmatic hernia.
- A premature baby has, or is suspected to have, difficulties as a result of hypoxia (even though the longer term prognosis may not yet be known).
- A premature baby has been born with a disability or disabling condition.
- A premature baby has a life-threatening illness such as cancer or leukaemia.

AND

- The baby is likely to be inpatient for at least five days or longer.

AND

- The applicant family meet Family Fund’s other criteria.

The following circumstances indicate that a baby may not meet Family Fund’s criteria:

- A baby born early who may be a little slow to feed, but is likely to make progress in the next few days.
- Any baby who is not disabled or significantly premature.
- A baby who is “small” or “early for dates”.
- Babies who have come into hospital for planned surgery or tests.
- Babies who are not likely to be inpatient for more than five days”.

*If a baby is currently inpatient but will be transferred to another hospital and continue to be inpatient there, then an urgent application can be made. These circumstances will be taken into consideration when considering how Family Fund may be able to offer help.

Family Fund is not able to offer retrospective help for expenses or costs already incurred. All grants are discretionary and subject to available funding at any time.

This is a general guide for premature babies. Details about the general Family Fund disability criteria can be found in the Urgent Referral booklet. Contact the urgent helpline on 01904 550804 or email urgents@familyfund.org.uk for more information about whether an application may be suitable.

- Registered user
- Urgent application
- Short term
- Means tested
- Staged payments
The Butterfly Project

Clinical practice points – things to think about for staff

These practice points are not intended to be used as a checklist, but as an aide-memoire to help to ensure staff have given parents the opportunity to consider important issues and support with practical arrangements.

Every parent and family is different – think carefully about what to speak with parents, and what to say. Many of these practice points may not be relevant for some families.

When a twin/multiple dies before delivery

- Do parents want to see the twin who died after the birth?
- Do the parents want to spend time with this twin?
- Do the parents want to have both twins together for a period of time (if feasible)?
- Do the parents want to have a memorial ceremony or funeral?
- Ensure parents know where the body of their twin will be in the few days after
Newlife

Newlife Nurses are the gateway to information, grants and care. They run a national hotline which supports and informs families, whether they have just been told of their child’s disability or need help accessing local services. The Newlife Nurse Helpline is free, confidential and trusted.

Nothing is too small or too important to discuss with a trusted Newlife Nurse. In addition, Newlife Foundation offers grants for essential medical equipment. If the statutory health and social care services cannot help, Newlife Nurses can propose a grant for equipment direct from Newlife funds or they can provide information of grants available nationally from other sources.

Newlife Nurses can be contacted by:

- Calling our Free Nurse Helpline phone number 0800 902 0905 (free from UK landlines) (Monday to Friday 9.30am - 5.00pm (Wed 9.30am to 7.00pm) - answer phone facility outside normal hours)
- Using our Live Nurse Chat Service
  Click on the icon top right, fill in grey, the service is offline but you can leave a message.
- Sending an email directly from our website or via nurses@newlifecharity.co.uk

Moving Stories - Disability Living Allowance

Newlife’s call on Government to extend the mobility element of Disability Living Allowance to families of seriously disabled and terminally ill under 3’s to help meet their travel costs including frequent hospital or clinic visits and transporting essential equipment.

Parents of a child born with a disability or life-limiting condition or whose child becomes disabled during the early years can apply for and receive the care element of Disability Living Allowance while the child is an infant. But they are excluded from the mobility component of the benefit. It is accepted that these children have additional care needs but not additional mobility needs; yet the costs of transporting a disabled child can be huge – such as the cost of specialised car seats from £260 to £2500 or buggies up to £3000, not to mention the costs of frequent travel to medical appointments and hospital car parking. In 2001, the mobility benefit criteria were changed to lower the minimum age from 4 years to 3 but this still excludes a large number of infants. In fact, although very young children with severe mobility problems can apply for the mobility component of DLA from the age of 3, others with less serious conditions but still having mobility problems may have to wait until they are at least 5. So our campaign proposes that the minimum age of 5 years for the Disability Living Allowance Mobility Component should be reduced to 3 months in line with the DLA care criteria to enable the families of children with significantly additional mobility needs to access this benefit.
Antenatal Results and Choices (ARC)

Helping parents and professionals through antenatal screening

ARC is the only national charity helping parents and healthcare professionals through antenatal screening and its consequences.

Around 800,000 women in the UK become pregnant each year. More than 10,000 will be told there is a risk their baby has a serious fetal anomaly. Naturally, this causes a great deal of anxiety and uncertainty. Most parents will ultimately be reassured the pregnancy is progressing as expected. Sadly, some will receive the devastating news that their baby has a serious, sometimes lethal condition, or might be told that the outlook is very uncertain.

ARC offers non-directive information and support to parents before, during, and after antenatal screening; when they are told their baby has an anomaly; when they are making difficult decisions about continuing with or ending a pregnancy; and when they are coping with complex and painful issues after making a decision, including bereavement.

Need support?

ARC News

"Illumina" becomes ARC's latest partner
Published: Tuesday 28 May 2013
We are pleased to announce that Illumina have joined ARC as a corporate partner.

"Genesis Genetics UK Ltd" becomes ARC's latest partner
Published: Tuesday 28 May 2013
We are pleased to announce that Genesis Genetics UK Ltd have joined ARC as a corporate partner.

More news...
Child Funeral Charity
www.childfuneralcharity.org.uk

Arranging a funeral for a child is something no-one can imagine having to do. And at a very emotional time, financial pressures in paying funeral expenses can add to the distress.

Child Funeral Charity (CFC) assists families financially in England and Wales who have to arrange a funeral for a baby or child aged 16 or under. Whilst many funeral directors, the clergy and most celebrants do not charge fees, there are other funeral related expenses that bereaved parents struggle to find.

Financial support is available from us to help with such funeral costs, together with practical advice and guidance.

CFC takes referrals and applications for financial support from professionals who have knowledge of the bereaved family and their circumstances.

Therefore if you are a:
- Funeral Director
- Celebrant or faith representative
- Bereavement Nurse or Midwife
- Hospice Manager
- General Practitioner
- Local Authority Registrar
- Hospital Bereavement Officer
- Hospital Medical Registrar, or
- other professional

Then you can refer bereaved families to us.

In order to provide financial support to as many bereaved families as possible, we are always fundraising. If you would like to support our activities, please click here.
Collaborative Working

- ‘In Reach’
- ‘Out Reach’
- 2 way process
- Knowledge of what services are available
- Sharing good practice
- Maintain relationships
- Named professional
Who do you refer to?

• Team based at GOS / Louis Dundas Centre
• Team based at ShootingStarChase
• Team based at Evelina
• Children’s hospices
• Community nursing team
• Rainbow Trust
Collaborations
# CONTACT NUMBERS

**London Neonatal Operational Delivery Network**

<table>
<thead>
<tr>
<th>Community based paediatric palliative care teams</th>
<th>0207 829 8678</th>
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<tr>
<td>The Louis Dundas Centre, GOS Hospital (London)</td>
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<tr>
<td>Symptom Care Team, Shooting Star House</td>
<td>01483220990</td>
</tr>
<tr>
<td>Dr AK Anderson</td>
<td>07867800927</td>
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<tr>
<td>Jane Cane (CN1)</td>
<td>07868050093</td>
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<tr>
<td>Paediatric palliative care team (SE)</td>
<td>0207 186 7198</td>
</tr>
<tr>
<td>Evelina (SE)</td>
<td>0207 186 7198</td>
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<tr>
<td>Kaleidoscope Palliative Care Nursing Team (K&amp;C, H&amp;F &amp; Westminster)</td>
<td>0207 266 8840</td>
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<tr>
<td>Life Force (Camden, Haringey &amp; Islington)</td>
<td>0203 318 1950</td>
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<tr>
<td>Newham Diana Nursing Team (Newham)</td>
<td>0208 475 8580</td>
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<th>Hospices within London Neonatal Operational Delivery Network</th>
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<tr>
<td>Demazza House (SE)</td>
<td>01795845200</td>
</tr>
<tr>
<td>Elenor (SE &amp; Kent)</td>
<td>01474 320007</td>
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<tr>
<td>Haven House (NC &amp; NE)</td>
<td>0208 505 9944</td>
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<tr>
<td>Little Havens (Essex)</td>
<td>01292 220350</td>
</tr>
<tr>
<td>Noah’s Ark (NE &amp; NC)</td>
<td>0208 449 8877</td>
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<tr>
<td>Richard House (NE &amp; SE)</td>
<td>0207 540 0243</td>
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<tr>
<td>Shooting Star (SW &amp; NW, Surrey)</td>
<td>01932 823 100</td>
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### Support resources

- Rainbow Trust: rainbowtrust.org.uk/neonatal-support
- Resources: www.londonneonatalnetwork.org.uk
Neonatal Palliative Care

• NOT end of life care
• NOT giving up on babies and their families
• Providing positive and therapeutic actions from the moment of recognition / identification
• Alongside active treatment
• Quality of life and support for the whole family

Continuum of care throughout the baby’s life and beyond
“The expectation that we can be immersed in suffering and loss daily, and not be touched by it, is as unrealistic as expecting to be able to walk through water without getting wet”.
(Remen1996)
Care for yourself

- Share experiences
- Good communication
- Secondary trauma
- Confidence
- Framework to support staff

- Debrief
- Mortality & Morbidity meetings
- Reflection
- Counselling
- Faith
- Family
- Outside work
Education and Training

- Short sessions
- Cot side
- Accessible
- Relevant and current
- Inter-professional

- Research-progression
- Nursing
- Pushing boundaries
- Reflection
- Supervision
Hospice Study Days

Friday May 26th
• Shooting Star, Hampton

Wednesday 26th July
• Haven House, Wood Green

Friday 10th November
• Shooting Star, Hampton
Supporting professional development
www.elearnicpcn.org
References & Resources

• APPM (2017) Association Paediatric Palliative Medicine Formulary  www.appm.org.uk
• CBUK- www.childbereavementuk.org
• London Neonatal Network www.londonneonatalnetwork.org.uk
• Redshaw M, Rowe R, Henderson J, (2014) Listening to parents after stillbirth or the death of their baby after birth. NPEU, Oxford
• Royal College of Nursing (2013) Breaking Bad News: Supporting parents when they are told their child’s diagnosis. London
• Organ Donation- www.organdonation.nhs.uk
• Rainbow Trust- www.rainbowtrust.org.uk
• Remember My Baby www.remembermybaby.org.uk

UK Map of Neonatal Units & Hospices Neonatal Data Analysis Unit (NDAU)
https://www.google.com/maps/d/viewer?mid=zvO6tbi1tNpl.k6W-xh0w52nM