

VOLUNTEER STORIES



Gemma was born at 28 weeks weighing 650g. She got NEC at 6 weeks and needed surgery. She was left with a stoma for around 2 months. Today Gemma is a happy 10 year old.



Niamh was born at 38+4 weeks, she was 4 weeks old when she developed NEC. Niamh had surgery and stoma, reversal at 12 weeks old. Now 3 years old she has nutritional needs and a speech delay.



Freddie was born at 29 weeks weighing 1.3kg. At 10 days Freddie was diagnosed with severe NEC. Freddie came home on TPN 12 hrs. 7 nights a week. He is now 4 years old has short bowel disease, cerebral palsy and developmental delay.



Charlie & Ollie were born at 32 weeks. They were 3lb 4oz and 3lb 14oz. Ollie had pulmonary atresia. On day 9 Ollie developed NEC, very sadly Ollie didn't survive. Charlie is now 5 years old.



Nicola is thought to be one of the eldest NEC survivors. Born at 29 weeks in 1980. Nicola's bowel perforated in 3 places before emergency surgery and didn't have her reversal until she was 13 months old. Nicola gave birth to twin boys at 28 weeks, her son **Freddie** also developed NEC and is now 4 years old.

ABOUT NEC UK

NEC UK is a registered charity which is parent led and formed from a group of parents of babies affected by Necrotising Enterocolitis.

We offer support to families affected by NEC at any stage of their journey and of mixed outcomes through both emotional and practical support.

We raise awareness of NEC through our social media platforms, events and are one of the key collaborative organizations and groups to declare May 17th as global NEC Awareness Day.

We collaborate and partner with other charities and work with clinicians, researchers, associated professionals, neonatal networks and hospitals. We participate in parent focus groups, conferences and presentations to represent the voices of NEC families and help to give NEC a platform to be heard.

We support research and studies into NEC and in 2018 we were able to contribute our first funding towards NEC research.

NEC UK is registered as a stakeholder with The National Institute for Health and Care Excellence (NICE) who provides national guidance and advice to improve health and social care



NEC UK Charity
42 Long Hill Rise Annesley,
Nottingham,
NG17 9FG
Enquiries: 07375813907
Email: info@necuk.org.uk
Registered Charity 1181026

www.necuk.org.uk

What is NEC?

Necrotising Enterocolitis (Nek-roh-tie-sing En-ter-oh-coh - lie-tis) also shortened to NEC (Nec) is an inflammation of the bowel that can cause damage to a variable extent. It usually causes a temporary intolerance of milk feeds but sometimes the bowel may become so damaged that parts of it die. NEC can affect a small part of the bowel or sometimes the whole bowel may be affected. NEC is mostly seen in premature babies but can sometimes occur in term babies.

Example of a Healthy & Damaged Bowel



How can we try to prevent NEC?

Research has proven that breast milk significantly reduces the risk of NEC occurring. Breastfed babies aren't immune to NEC, however if NEC occurs breast milk can help reduce the severity which is one of the reasons parents are encouraged to express their colostrum (first milk) as early as possible after birth. For different reasons Mums may not be able to express their own or enough milk and donor human milk may be a consideration. Donor milk is rigorously tested and pasteurised in medically specialist milk banks to ensure its safety. Sometimes Probiotics may be given to help reduce the risk of NEC.

Important to know

Not all babies will develop NEC. Sometimes a baby may present in a way that causes suspicions of NEC and will be cared for similarly as a precaution. NEC is very individual to each baby and the medical team caring for your baby will be best able to answer any questions you have.

Researchers, scientists and clinicians are working hard to understand more of the mechanisms to NEC, but the exact cause remains unknown.

What are the signs & symptoms of NEC?

Sometimes babies can display all, some or no early indication of NEC. These symptoms are;

- Increased gastric aspirates from the NG Tube
- Swelling, tenderness and discoloration of the tummy
- Blood in baby's poo
- Bringing up a green fluid called bile Increased apnoeas and bradycardias, low blood pressure.
- Temperature changes can indicate something is going on with baby but isn't necessarily as a result of NEC. We encourage parents to always share any concerns they have with their baby's medical team, including if parents have the feeling that something just seems off with baby today.

How is NEC treated?

Initially when a baby is suspected as having NEC feeds are stopped temporarily to allow the baby's bowel to rest. Baby will usually receive antibiotics and other supportive measures which might include support with their breathing, fluids and medications. Sometimes babies may require surgery for more investigation if their condition isn't improving or if they have very suddenly become unwell. Depending on a baby's condition and where they are being cared for, some babies may need to be transferred to an intensive care area of a neonatal unit or possibly to a different hospital. Sometimes transfers can happen quite fast and may be unexpected which can feel scary and upsetting for families, please reach out for support.

Outcomes

Many babies can and do recover really well from NEC, including those who may require surgery. Sometimes NEC can re-occur in a baby. The longer-term impact of NEC is still to be fully understood but we know babies particularly those who have had surgery may experience developmental challenges later. NEC can be life threatening and sadly not all babies survive.

Support for Families

NEC UK offers emotional and practical support to families affected by NEC at any stage of their journey and of different outcomes. Here are some of the ways we do this:

Peer to peer support in the "NEC UK Charity Support Group" which we use on the Facebook platform. The group is for families only and posts are not visible to anyone outside of the group.

E-mail support at info@necuk.org.uk

NEcessaries parents care packs which contain emergency food, toiletries and other essential supplies for both parents in hospital. Designed by parents for parents.



Breast Pumps are brand new manual pumps in sealed boxes, available to Mums of babies who have a medically identified risk of developing NEC and for Mums of babies recovering from NEC to continue expressing while away from the hospital. Please note our pumps are not intended for hospital use.

Nappy Support assistance for babies and children identified as having an above average usage of nappies as a result of NEC and who meet the charity's criteria.

Bags of Love are designed for bereaved families and contain keepsake items such as a small teddy bear, a wooden heart that baby's name or a short message parents can write on, personalised word art in a card, a heart shaped candle and some flowering seeds to sow because together we remember with you.

Kangaroo Care Pack

Here at NEC UK we encourage and promote Kangaroo Care by sending our local Hospitals Kangaroo Care Hampers containing the essential items to promote this.

