

# NEC and parents: Putting babies' best interests first

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# About Bliss



- Our vision:

Every baby born premature or sick in the UK has the best chance of survival and quality of life

- Our mission:

Bliss champions the right for every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research

- Our values:

**Trusted**

**Supportive**

**Ambitious**

# Bliss' 2016-2019 strategy

## We will improve the lives of babies born premature or sick



We will support parents of babies born premature or sick to be as involved as possible in care and decision-making for their babies.



We will support neonatal professionals to deliver high quality baby-centred care and to involve parents actively in their babies' care.



We will place premature and sick babies' voices at the heart of decision-making to ensure that their best interests are always put first.



We will support research that can tangibly improve outcomes for babies born premature or sick.

[bliss.org.uk/our-strategy](https://bliss.org.uk/our-strategy)

# Policy context (1)

## Ensuring babies are born in the right place

- Need to ensure that all women <27 weeks are delivered in centres with a NICU
  - Clear network pathways in place
  - Close working with fetal medicine / maternity services
  - Process for timely in-utero transfers
  - In 2014/15, nearly half of transfers (5,578) across the UK were for escalation of care

# Policy context (2)

## Delivering timely and consistent neonatal transport services across the country

- UK national standards include:
  - Transport services should be available 24 hours a day, 7 days a week
  - For time-critical transfers, transport team should set off from base within 1 hour of phone call, in at least 95% of cases



# Bliss

for babies born  
premature or sick

Transfers of premature  
and sick babies

**Bliss**  
for babies born  
premature or sick

# Bliss neonatal transport report



- Wide variation across the UK in transport provision:
  - 1 in 4 neonatal transport services does not have dedicated transfer team at night
  - 3 out of 17 services do not have any dedicated road vehicles equipped for neonatal transport
  - 8 out of 9 services which provided data were unable to meet NHS standard for time-critical transfers
  - Half of transport services unable to provide 24-hour single point of contact (for access to cot / maternal bed availability, and the transfer service) during 2014/15
  - Half of neonatal transport services reported staffing gaps in 1-week snapshot

# 16,000 transfers of premature or sick babies take place every year

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for babies born premature or sick



**4 out of 17** services did not have a dedicated team to move babies at night



**No air transport** for smallest and sickest babies in England

## HOSPITAL

**8 out of 9** services unable to meet response speed target



of services reported staffing gaps

**15%**

of emergency transfers were because the unit was full





# Parental involvement (1)



## Family-centred care at the heart of all neonatal service provision

- Importance of parental involvement in all aspects of decision-making and care from admission onwards
  - Welcoming environment on the unit
  - Involvement and participation in ward rounds
  - Support to provide hands-on care
  - Provide information and build confidence

**Parents know their babies best...**

**...so health professionals  
need to listen to parents  
when they say something is  
wrong with their baby**

“If you are a mum and you think there is something wrong with your child: trust your instincts. Push the doctors and nurses and try to find someone with a second opinion. **Because if something doesn’t seem right to you then you’ve got to make sure something is being done about it.**”

# Parental involvement (2)

## Parental involvement if NEC is suspected / transfer is required

- Clear communication and support is key
  - Parental input to transfer decision if possible
  - Facilitate parents to transfer
  - Receiving unit to support and accommodate parents as well as baby on arrival
  - Understand they will be terrified

**Bliss information available here:**

**<http://www.bliss.org.uk/necrotising-enterocolitis-nec>**