

# Reaching every baby born premature or sick

Bliss strategy summary  
2016-2019



**Bliss**  
for babies born  
premature or sick

# At Bliss, our vision is simple: that every baby born premature or sick in the UK has the best chance of survival and quality of life

The time babies spend on a neonatal unit and the care they receive are vital to determining their long-term development. That's why, over the next three years, Bliss' focus will be reaching every single baby and their family with our work.

With 90,000 babies born needing neonatal care each year, this is an ambitious goal. But we know, from research published in our *Bliss baby report 2015*, that neonatal units are being stretched to the limit and are falling behind on vital safety standards. With neonatal care hanging in the balance, Bliss' work is needed now more than ever.

Over the last five years Bliss has driven significant improvements in care for premature and sick babies. But we know that we are not yet reaching all babies and their families who need our help. Last year, over 3,100 people told us about their experience of neonatal care and what they wanted to see from Bliss

in the coming years. Parents and families told us that they want access to information and support as early into their neonatal journey as possible, and that Bliss needs to do more to provide this consistently in every neonatal unit across the UK.

Supporters told us that Bliss has an important role to play in campaigning for change in neonatal care and supporting life-changing neonatal research. And almost 80 per cent of people said that working directly with neonatal units should be a priority for Bliss.

This feedback has informed our four new strategic priorities. We believe that the best way to significantly improve the lives of babies born premature or sick is by empowering parents to be involved in their care; supporting neonatal units and professionals to improve their standards of care; ensuring babies' voices and best interests are always represented in decision-making; and by investing in life-changing

research. These four areas will be our priority for the next three years, and we have set out a clear and ambitious strategy to achieve them.

I am hugely grateful to all our supporters who helped us develop this strategy, and to the thousands of families, volunteers, fundraisers, campaigners, health professionals and partners who will help to make it a reality. We couldn't hope to achieve our goals without the generosity of our supporters and the determination of families and volunteers: **together we can make a real and lasting difference to every baby born premature or sick in the UK.**

**Caroline Davey**  
Chief Executive

# Our strategy



# Our vision, mission and values

## Vision

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

## 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.

**Baby loss and sickness can be very taboo, but when you do something like fundraising you suddenly find people opening up. To be able to look up to the sky and say there is a star in Isaac's name from Bliss will be a very powerful moment for us all, and to realise we have achieved that by supporting other families and babies that need special care makes it all the more special.**

### Wendy Langdown

Mum to Isaac who died 11 hours after his premature birth and Precious Star Fund holder

## Values

### Trusted

We are entrusted to give voice to all babies born premature or sick. We believe that trust is earned and our actions must always be based on what is best for babies.

### Supportive

We believe that developing supportive relationships is at the heart of what we do, and only by supporting others are we able to achieve our goals.

### Ambitious

We always go the extra mile to deliver excellence and seek improvement in all we do.

Underpinning all of our work are our amazing supporters, and we are continually grateful for the generosity and enthusiasm of individuals who take part in events, fundraise in their communities, make regular donations, and remember us in their wills. It is thanks to these incredible people that we are able to make a difference to the lives of premature and sick babies and their families.

# Our objectives



# 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.



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

By empowering parents with the knowledge and skills to care for their baby we will help to build their confidence and help them provide the best possible care to their babies, however long they live and however long their stay in neonatal care. Parental involvement in care has proven health and developmental benefits for babies and can improve bonding and emotional wellbeing for the whole family.

**One day I saw a Bliss leaflet and it was like a light had suddenly been switched on and all of a sudden I wasn't alone any more. I went to the Bliss website and read through stories from other parents and found out about the various terms I'd heard on the unit. After reading through everything I suddenly had the confidence to ask the doctors questions and understand what was really happening. I started asking to hold Scarlett, rather than waiting for nurses to offer. I helped to tube feed her and I even gave Scarlett her first bath.**

**Georgia Melbourne**

Mum to Scarlett born at 28 weeks

**Bliss will:**

**Ensure our information meets the needs of parents with a baby in neonatal care by reviewing and developing it across platforms and:**

- Improving our information for parents of babies born full term and sick.
- Providing practical information for parents to support their baby's development after they have left hospital.
- Signposting to local and national organisations offering specialist support.

**Provide emotional support to parents in every part of the country through our volunteer-driven support services by:**

- Building on our face-to-face volunteer services and volunteer-led family groups.
- Increasing awareness of our volunteer-led helpline and online messageboard, in partnership with Netmums.
- Working in partnership with other charities to pilot opportunities to offer comprehensive bereavement support to parents who have lost a baby.

**Raise awareness of our services for parents as early as possible in their neonatal journey by building and developing a communications programme.**



REMOVABLE CURTAIN  
5/15/16  
NO ENTRY

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

By working hand-in-hand with neonatal units we can support them to improve their facilities for babies and families and deliver high quality developmental care, which has proven benefits for babies. Bliss will take a leading role in training and sharing good practice among health professionals. We will facilitate a community where peers can support each other to provide excellent care.

**Charities like Bliss have been at the forefront of improvements in care for babies, especially with powerful tools like the Bliss Baby Charter. Bliss has a strong presence in neonatal units, their support in achieving 'gold standards' such as one-to-one nursing care for all intensive care babies is invaluable.**

## **Carol Buxton**

Family Support and Infant Feeding Specialist at Queen Alexandra Hospital, Portsmouth.

## **Bliss will:**

### **Work with neonatal networks to reach all neonatal units with our Bliss Baby Charter audit and accreditation programme by:**

- Providing support to enable units to audit their practices and develop and implement meaningful plans to achieve change which will benefit babies and their families.
- Supporting units to make practical improvements to increase parental involvement in their baby's care, through the Bliss Baby Charter Grant Fund.

### **Support neonatal professionals to deliver high quality care by:**

- Rolling out an accredited developmental care training programme.
- Working with neonatal units and networks to reach a significant proportion of the neonatal workforce across the UK.

### **Develop a Bliss professionals' network by:**

- Providing regular and accessible information, including service development, as well as sharing good practice to promote excellence in care.
- Fostering peer relationships and networks for neonatal professionals to share and learn together.



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

By building on the success of the *Bliss baby report 2015*, we will create bold, evidence-based campaigns to represent the voices and interests of babies in neonatal care. With the help of parents and charity partners, our voice will be louder, allowing us to secure positive changes in policy, investment, and standards of care for babies.

**When the care of babies is compromised, so too are their chances of life-long health. This will increase their future requirements for healthcare and diminish their ability to become productive members of society. That's why we support Bliss' call for more investment in newborn care.**

## **Professor Neena Modi**

President of the Royal College of Paediatrics and Child Health and Consultant Neonatologist commenting on the *Bliss baby report 2015*

## **Bliss will:**

### **Campaign hard to ensure the delivery of high quality care for every baby born premature or sick by:**

- Building on the success of the *Bliss baby report 2015* in England and releasing reports for Scotland, Wales and Northern Ireland to ensure the delivery of national neonatal standards.
- Making the case for the right levels of funding to deliver safe, high quality neonatal care.
- Ensuring that commissioning incentivises babies being cared for in the right place.
- Delivering a long-term sustainable plan to recruit, train and retain a neonatal workforce.
- Improving support for families to enable them to be as involved as possible in their babies' care.
- Working with maternity services to ensure that sufficient transitional care is provided so that babies are not separated from their mothers if they don't need to be.

### **Represent babies' voices and encourage and support others to do the same by:**

- Capturing the views and experiences of parents and using this to inform all of our work.
- Recruiting and supporting parents to input into policy and decision-making at local, regional and national levels.
- Building and supporting our network of active campaigners.

### **Work with other charities to develop policy and campaigns to reduce infant mortality across the UK.**



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

Research has the potential to save lives and improve the quality of life of premature and sick babies for generations to come. We will make the biggest possible impact on babies' lives by identifying and funding research projects and supporting large scale projects. We will support parental engagement in research to ensure that babies' interests are being represented. And, by sharing research findings among professionals we will help to actively improve care.

**We had limited information about early nutrition before now but this study has given us clear results and lots of other important information about how to manage nutrition in the critical period after a baby is born. This research should help improve the survival chances and life quality of future generations of premature babies.**

## **Dr Colin Morgan**

Consultant Neonatologist at Liverpool Women's Hospital and lead researcher on the ground-breaking SCAMP study, funded by Bliss

## **Bliss will:**

### **Fund and support research that can make the biggest difference to the lives of babies born premature or sick by:**

- Identifying our key priorities for funding and developing an outcomes framework.
- Influencing projects that provide opportunities to increase the body of neonatal evidence and deliver positive change for babies.
- Building on and expanding our work engaging parents in research.
- Identifying opportunities to share research findings to deliver maximum reach and impact.
- Ensuring our information for parents reflects the latest research and evidence.

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