



2019-2022

Bliss strategy

Giving every baby born premature or sick
the best chance of survival and quality of life

Bliss
for babies born
premature or sick

40 years of putting babies at the heart of everything we do



Achieving the best outcomes for babies born premature or sick has been at the heart of everything we do at Bliss since we were founded 40 years ago in 1979.

More recently, in 2016, we set our ambition to give **every** baby born premature or sick in the UK the best chance of survival and quality of life; a goal we will continue to work towards with this new strategy.

The impact of our work for babies over that period can be found on page 4. We're very proud of the difference we've made but as the number of babies born needing neonatal care continues to rise, our work is far from done.

We've had successes beyond our expectations over the last three years, such as the uptake of the Bliss Baby Charter among more than 89% of neonatal units across the country, widespread campaigning success across all four UK nations, and recruiting and training more neonatal unit volunteers. But, our resources have been stretched along the way as we have sought to deliver more for babies and families. There has been a higher demand on our services than expected, or than we can sustainably manage going forwards, and as a result we will be delivering some of our work differently in future.

As we set our new strategy to start in the spring of 2019 in the context of a challenging external and fundraising climate, we are taking a cautious approach to fundraising and service delivery in the first year of this new strategy, driving up value for money in everything we do and delivering core services that can bring the biggest benefits for babies.

We will also prioritise seeking the additional funding we need to deliver ambitious projects in the second and third years of this strategy, including new digital services and specialist support for those families we're not currently reaching.

This strategy sets out what we will achieve and how we'll make best use of the excellent resources we have, and the additional impact we could have for babies with the funding we are seeking to do even more. With this model, we will ensure we reach and support more babies in neonatal care by achieving the kind of sustainability we need to succeed over the next few years and beyond.

As we enter our 40th anniversary year, we have an opportunity to reflect on the changes and developments made in neonatal care as a result of Bliss' work since we were founded. It's also a chance to celebrate the contribution of all those people who have contributed to our work since 1979 who believe, as we do, that every baby deserves the best start in life and who make our work possible every day.

Thank you for your ongoing support and for working with us to give every baby born premature or sick the best chance of survival and quality of life.

A handwritten signature in black ink, appearing to read 'Caroline Lee-Davey'.

Caroline Lee-Davey
Chief Executive



“Bliss volunteers are amazing”

“28 weeks into my pregnancy with twins, the doctors told me they were concerned that one of my twins wasn’t growing as they should be. It was very likely they would need to be delivered early.

“After being admitted onto the labour ward with very high blood pressure at 30 weeks and 2 days, I was told I’d need to be transferred to the nearest NICU able to host us – 31 miles away from our home.

“I gave birth the next day and was discharged a few days later but began to panic because my husband, Kurt, and I don’t drive. I was all set to sleep in a chair by the incubators but then luckily a parents’ room was available on the ward.

“The early days of parenting were a whirlwind. There were so many low moments: I struggled to express milk, and daily blood tests took their toll on Isla who required several blood transfusions and didn’t gain weight as quickly as her brother, Jakob. It was a constant worry.

“No one will ever understand how much the NICU staff helped us through those darkest moments and the Bliss volunteers who take time out of their own lives to support strangers are truly amazing. The other work Bliss does is also wonderful – the research they support is invaluable to babies and families in years to come, and the way they champion the need for parents’ rooms on units is vital. I don’t know how we would have done the journey to the hospital every day.”

**Claire, mum to Jakob and Isla,
born at 30 weeks and 3 days**



Jakob is still bigger than his sister but Isla is catching up

Our impact: 2016-2019

In 2016, we set our ambition to give **every** baby born premature or sick in the UK the best chance of survival and quality of life. Here is just some of what we have achieved.



Investing in babies' futures

We supported research to tangibly improve outcomes for babies born premature or sick.

- Our first research grant was awarded to a team at Oxford University who are finding ways of measuring and soothing babies' pain, using their parents' touch, so that every baby's journey in neonatal care is as painless as possible.
- We've supported patient and public involvement in a wide range of neonatal research projects, including acting as a co-applicant to represent the voices of babies and their parents in over ten funded projects.



Raising standards of care

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

- More than 89% of neonatal units across the UK are making improvements to care through our flagship Bliss Baby Charter programme.
- Over 1000 healthcare professionals attended FINE* training or a Bliss Study Day to build their skills in delivering family-centered developmental care.

*Family-Infant Neurodevelopmental Education



Standing up for babies

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

- Our series of Baby Reports looking at neonatal care across the UK shone a light on issues affecting care for premature and sick babies, and greater investment and service change is now being taken forward in Scotland and England.
- We successfully campaigned for a £1.5m Neonatal Expenses Fund in Scotland to help parents with food and travel costs – keeping them together with their babies at the most critical time.
- With many partner charities, we successfully campaigned for the Parental Bereavement (Leave and Pay) Act, which will provide employed parents who lose a baby with two weeks of paid leave.



Empowering parents every day

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

- 12,448 parents across England, Wales and Scotland received cot-side support from trained Bliss Champion volunteers.
- We developed new ways to provide parents with the information they told us they need, including more online information, videos and our first podcast – NICU, SCBU and You – focusing on parents' mental health.

Our 2019–2022 strategy



Our vision, mission and values

Our vision

Bliss' vision is that 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

Our values support a culture at Bliss which promotes a positive workplace and enables us to recruit and retain a skilled and passionate team. They also set a standard for how we aim to work with parents, professionals and supporters.

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.

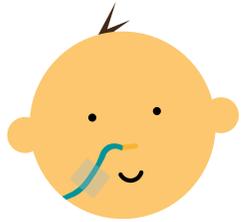
Supportive

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.

Our objectives



For more babies born premature or sick to survive.



For babies born premature or sick to have well-supported parents playing an active role in their decision-making and care.



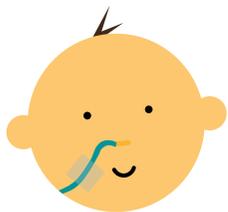
For babies born premature or sick to be cared for in neonatal environments that best support their development.



For babies born premature or sick to benefit from neonatal research that can lead to practical improvements in their care.



For babies born premature or sick to receive high-quality care within a neonatal health system which is appropriately funded, structured and staffed.



For more babies born premature or sick to survive

The UK has a high neonatal mortality rate when compared with other EU countries. Our poor international standing is the driving force behind the Government's ambitious aim to halve neonatal deaths and stillbirths in England by 2025. At Bliss, we're ambitious too and will work in partnership with other charities and professional bodies to ensure that there is a sustained commitment in England and across the UK to deliver on this, and to ensure that the opportunity to learn from every case of neonatal death is taken.

We will:

- work in partnership with other charities to ensure the Government in England remains focused on delivering the policy changes needed to meet its target to halve neonatal deaths and stillbirths by 2025 – and that there is a sustained effort across Scotland, Wales and Northern Ireland to do the same.
- work alongside other charities and professional bodies to ensure that lessons are learned from every case of neonatal death and shared at a national level.

“It is only through collaboration that we will be able to reduce the number of neonatal deaths and stillbirths; it is a great privilege for Sands to work with Bliss to achieve this aim.”

Clea Harmer, Chief Executive, Sands



For babies born premature or sick to have well-supported parents playing an active role in their decision-making and care

Supporting parents to play a hands-on role in their babies' care has proven health and developmental benefits for babies and can also improve bonding and wellbeing for the whole family. But many parents tell us they find this very difficult in the neonatal environment. This can lead to feelings of helplessness and isolation. Across Bliss services we aim to ensure that parents of babies in neonatal care are equipped and encouraged to play an active role in their care.

We will:

- develop information for parents on the subjects they tell us will most help them to be actively involved in their babies' care.
- facilitate the provision of emotional support for parents through both our volunteer-delivered services and online peer communities.
- share good practice in how to involve families in their babies' care with neonatal healthcare professionals through our Bliss Baby Charter programme and Bliss Excellence Network.
- continue to focus on reducing the barriers that prevent many parents from being actively involved in their baby's care on the neonatal unit, including insufficient parent accommodation, facilities and support.
- work with partner charities to promote the delivery of high quality bereavement care, and support for parents in making decisions at the end of their baby's life.
- develop parent information and promote it through channels that enable us to reach the most parents possible and, with additional funding, develop information in a variety of formats to make it as accessible as possible for parents.
- with additional funding, work in partnership with communities of parents we currently do not reach effectively to pilot new information and support services such as webchat and text services.

**"The Bliss information motivated us and helped us gain more knowledge about what we were going through."
Mitchell, dad to Louis who was born at 32 weeks**



For babies born premature or sick to be cared for in neonatal environments that best support their development

Developmental and family-centred approaches to care bring proven benefits to babies and families. By working hand-in-hand with neonatal units and taking a leading role in training health professionals, we will support them to share good practice and learn from each other.

We will:

- work with neonatal units to improve and increase the delivery of family-centred care, including hands-on parental involvement in care, through support with the Bliss Baby Charter.
- increase the number of health professionals trained in neonatal developmental care through the delivery of Family-Infant Neurodevelopmental Education (FINE) training.
- share knowledge and understanding of family-centred care through the Bliss Excellence Network, our online learning portal and peer-to-peer forum for neonatal healthcare professionals.
- fund and support research which increases evidence of how best to deliver developmental care and improve outcomes for babies.

“The Bliss Baby Charter has supported the neonatal team to focus on what really matters to families. This has made a vital difference every day to all the babies we care for.” Louise Rattenbury, Matron at the Royal Devon and Exeter Hospital, the first hospital in South West England to receive Bliss Baby Charter accreditation



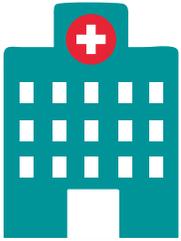
For babies born premature or sick to benefit from neonatal research that can lead to practical improvements in their care

Achieving the best outcomes for babies born premature or sick – now and in the future – is at the heart of everything we do. By funding and supporting research, we are investing in babies' futures through the continuous improvement of their care. Our focus is on research projects that involve parent perspectives to ensure that babies' needs are represented.

We will:

- fund research projects which will improve outcomes for babies, in line with our research funding framework, and will share their key findings widely to encourage the recommendations to be put into practice.
- support UK-based neonatal research projects to ensure they include input from parents.
- share research findings with neonatal health professionals through our Bliss Excellence Network to embed practical improvements in care.

"I have been fortunate enough to work in partnership with parents in neonatal research for many years, and Bliss have been absolutely crucial in supporting this. Parents provide unique insights and help us identify which outcomes of neonatal research they find most important." Dr Chris Gale, Consultant Neonatologist at Chelsea and Westminster Foundation Trust and lead researcher on several studies supported by Bliss



For babies born premature or sick to receive high-quality care within a neonatal health system which is appropriately funded, structured and staffed

Demand for neonatal services continues to grow as complex births become more common and survival of babies born at lower gestations improves. To ensure safe, high quality care, it is essential that additional resources are invested to build the neonatal workforce needed for the future. It is important that the workforce is sufficient in both numbers and skill mix to ensure babies have the best possible chance of survival and quality of life, and for ensuring parents are supported to be partners in their babies' care.

We will:

- work with politicians and decision-makers to ensure that resourcing and staffing of neonatal care is in line with evidence about what is best for babies.
- campaign for effective implementation of evidence-based neonatal quality standards.
- work with politicians and decision-makers to raise the profile and importance of neonatal care.

“Bliss supported me with writing to my MP and successfully campaigning for accommodation at the hospital when my daughter was on the unit. Being separated from her was heartbreaking so I know what a huge difference Bliss’ work can make.” Susanna, mum to Amy who was born at 34 weeks

Our core foundations

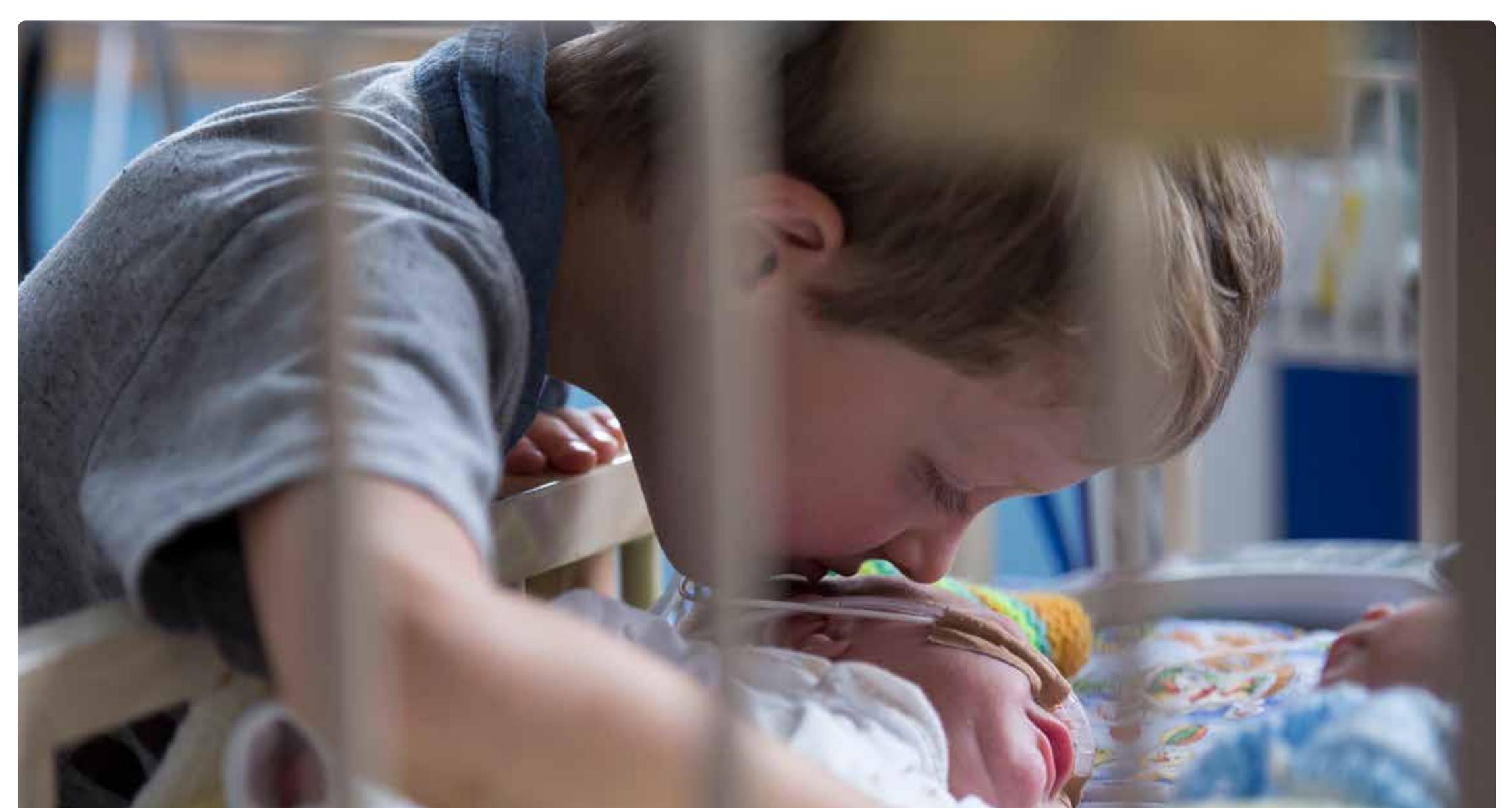
In order to have the greatest impact for babies, there are four core foundations that we will develop and apply across our programmes of work. **These are:**

Seeking to reach more parents – including those we aren't currently supporting – in order to make a difference for more babies

Raising awareness and understanding of our work, building on our heritage of 40 years of delivering positive change for babies

Measuring and sharing success with the people who enable our work to ensure we continue to improve and focus on making the biggest difference for babies

Making best use of technology to increase our efficiency as a small charity and improve outcomes for premature and sick babies



Bliss' vision is that every baby born premature or sick in the UK has the best chance of survival and quality of life.

We rely on the generosity of our supporters and partners to help us make this a reality. To find out more about what we do and how you can get involved, please get in touch.

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 ask@bliss.org.uk  bliss.org.uk  020 7378 1122

 Bliss, Fourth Floor, Maya House,
134-138 Borough High Street,
London SE1 1LB

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