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Reaching every baby born premature or sick: Bliss' new strategy

Over 90,000 babies are born needing neonatal care each year in the UK and at Bliss our vision is that every one of these babies has the best chance of survival and quality of life. Our most recent report, the *Bliss baby report: hanging in the balance*,[1] highlighted how over-stretched and under-staffed neonatal care is in England, and against this backdrop it is clear that Bliss' work is now more vital than ever. With the help of thousands of families, volunteers, fundraisers, campaigners and health professionals, we have developed a new three-year strategy. At its heart is a simple ambition: that every single baby born needing neonatal care, and every single one of their families, is able to benefit from our work.

In the years since the charity was founded in 1979, Bliss has helped to drive significant improvements in neonatal care. The new strategy builds on these achievements, and focuses particularly on delivering our core services consistently across the UK, as well as prioritising campaign and research activity that can improve the lives of babies born premature or sick. Following extensive consultation with stakeholders, our four strategic priorities for the period 2016-2019 are:

1. To support parents of babies born premature or sick to be involved in care and decision-making for their babies
2. To support neonatal professionals to deliver high quality baby-centred care and to involve parents actively in their babies' care
3. To place premature and sick babies' voices at the heart of decision making to ensure that their best interests are always put first
4. To support research that can tangibly improve outcomes for babies born premature or sick.

Supporting parents

Bliss has provided information and support for parents over many years and we know just how valuable this can be in helping parents to understand their baby's treatment, be involved in decision making, and have the confidence and skills to play an active part in their baby's care. Through our strategy survey we know that parents want access to this information and support as early as possible in their baby's neonatal journey – but we know that we are not yet achieving this.

Over the next three years we will be reviewing and developing our information to ensure it meets the needs of all parents with a baby in neonatal care. This includes the development of more information for parents of babies born at term but sick, practical information for parents to support their baby's development after discharge from hospital, and signposting information and referral to local and national organisations offering specialist support. Digital channels will also be prioritised as a key way of reaching parents with information.

Alongside this, our programme of volunteer-delivered emotional support will be expanded so that it is accessible to parents in every part of the country. We will extend the provision of face-to-face volunteer support to more neonatal units; raise awareness of our national volunteer-led helpline and online forums (in partnership with Netmums); and work with other charities to pilot specialist bereavement support services.

Supporting professionals

At Bliss we are proud of our history of working in partnership with neonatal professionals to improve care, and in recent years we have been pleased to build strong partnerships with units and networks through the Bliss Baby Charter Audit and accreditation programme. Over the next three years our aim is to expand this work even further, providing more in-depth support to enable more units to audit their practices effectively and develop meaningful action plans to achieve change.

One of Bliss' priorities is to support parents of babies born premature or sick to be involved in care and decision-making for their baby.

We also have a strong tradition of supporting neonatal professionals individually to improve their practice and champion new ways of working. Over the previous strategy period the Bliss Nurse role was piloted, funding dedicated family-centred care specialists on individual units and using their experience to understand how family-centred care can best be improved at a unit and network level.

The Bliss Nurses made a significant contribution to the experiences of families, as well as working tirelessly to promote the benefits of providing high quality family-centred care. However, in order to reach many more professionals and units over the next three years, efforts will be focused on rolling out more widely the FINE (family infant neuro-developmental education) developmental care training programme and building a stronger professional network to facilitate the sharing of information, good practice and peer support. Therefore, we will not be funding any more new Bliss Nurses.

Placing babies' voices at the heart of decision making

Bliss has always campaigned to raise the voices of babies born premature or sick and to achieve improvements in neonatal care. Following the publication of *Bliss baby report: hanging in the balance*, it is clear that our campaigning work is needed now more than ever as neonatal services are facing critical pressures on funding and staffing.

In the coming three years, we will build on the work that started with the launch of the *Bliss baby report*, rolling it out to the devolved nations and campaigning in each country on the core areas required to ensure the delivery of national neonatal standards and high quality, safe care for every baby born premature or sick. We will continue to work with parents and professionals to ensure that our campaigns reflect babies' needs and deliver positive changes in their care. Work will also be extended to recruit and support parents to input directly into policy and decision making at local, regional and national levels.

Supporting research

Bliss has been involved in key neonatal research projects over many years, and will continue to have an important role to play in supporting research. Over the next three years we will expand our programme of recruiting and supporting parental engagement in research; identify opportunities to share and disseminate research findings more widely; shape and influence projects that provide long-term opportunities to increase the body of neonatal evidence; and develop an outcomes framework for our own limited pot of research funding.

Looking to the future

This is an ambitious new strategy and we are hugely grateful to all of our supporters who helped develop it, and to the thousands of families, professionals, volunteers, fundraisers, campaigners and partners who will help to make it a reality. We could not achieve our goals without the generosity of our supporters and the determination of neonatal professionals, families, and volunteers: together we can make a real and lasting difference to every baby born premature or sick in the UK.

If you would like to read more about Bliss' new strategy, to be published in full in mid-March, please visit: www.bliss.org.uk

Above: Bliss will continue to campaign for the delivery of national neonatal standards and high quality care for every baby born premature or sick.

Left: Bliss has a strong tradition of supporting neonatal professionals to improve practice and champion new ways of working.

Reference

1. **Bliss.** *Bliss Baby Report: Hanging in the Balance.* Bliss: London 2015.