

Bliss: a new direction

Bliss, the special care baby charity, has a new focus for its work. It will invest £6m into Bliss Nurses to champion family-centred care. In addition regional offices will be established around the country and volunteer support will be expanded throughout the UK.

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This month my son turns six. It is a wonderful age, and we will of course be celebrating with a party, some presents and probably a big chocolate cake. Six years has passed very fast (though which parent doesn't say that!) and I still remember the moment he was born – but then it's not every day that you have a baby weighing a pound, born 15 weeks early, and rushed into intensive care. I didn't hold my son for over a week. It was four months before he left hospital. His younger twin brother never came home. I know that I am very lucky to have this bright and loving little boy in my family – and so birthdays are maybe just a little bit more special every year.

For doctors and nurses so attuned to neonatal care, experiences such as these can become normal. To families, it is anything but – for my family, as for the many thousands of families that Bliss supports every year, this is an alien, shocking and frightening world of wires and tubes, machines and drugs, life and death.

Bliss looks to the future

For 32 years Bliss has offered hope and support to families facing these incredible challenges, as well as working to support you, the dedicated nurses and doctors who these tiny babies are so reliant upon. We have bought equipment to help fit out units across the country. We have funded new research and training to improve care. We have fought with Government and the NHS to get much needed investment and to deliver on agreed standards. We have worked with thousands of families every year to help guide and support them and their babies through this most difficult time in their lives.

Last year we took a long, hard look at our work. We knew that we had been delivering good services to families and had achieved much through our research and with our campaigning activities (we no longer buy equipment of course). However, we could see that we were not achieving all of our mission. We needed to reach more families across the country

Keywords

Bliss; family-centred care; Bliss Nurses; partnership

Key points

Cole A. Bliss: a new direction. *Infant* 2011; 7(1): 123-25.

1. Caring for a premature or sick baby's entire family is now widely recognised as a crucial part of their overall clinical care.
2. Bliss is launching a national network of Family-Centred Care Nurses.
3. Bliss' new five year strategy is focused on working more locally and in partnership with other organisations and charities.



FIGURE 1 Lyndsey Hookway and Bobbie Everson sharing the Family-Centred Care Coordinator post at St Georges.

and we needed to do much more to drive the delivery of the new national standards of care.

This year we are restating our commitment to support premature and sick babies and their families in the most direct way possible – while they are in hospital, when they need us the most. To achieve this we are committing to establish a Bliss Nurse in each region in the UK – a minimum of 28 by the end of 2020. Bliss Nurses will not only support families through these challenging and difficult times, but also ensure that every neonatal unit has the capacity to deliver consistent, high quality family-centred care for babies and families.

First Bliss Nurses at St George's Hospital, South London

The first Bliss Nurse post will be at St George's Hospital in South London – working with First Touch, the charity supporting sick and premature babies at St George's and in conjunction with St George's Hospital and the South West London Perinatal Network. The post, a Family-Centred Care Coordinator, will be based in the neonatal unit. This first post is being shared between Lyndsey Hookway and Bobbie Everson. (FIGURE 1). They will work with the 600 families whose baby is admitted to the unit every year. They will also ensure that the unit has consistent, high quality family-centred care available, including promoting breastfeeding, kangaroo care and ensuring the right facilities and help are available.

Bobbie said, "The start of family life is extremely important and it has been shown that the way in which new mothers and fathers cope with their roles as



FIGURE 3 Father looking on at his baby, UCLH. 2009.

parents, greatly influences their own well-being and the physical and emotional health of their baby. Providing support and education in order to empower parents will help to improve the experience of the family while on the neonatal unit and beyond."

Lyndsey commented, "Family-centred care is such an important aspect of the treatment that babies on the neonatal unit and their families receive. I hope that this role will become a common feature of many neonatal units, as new training, evidence and policy is generated for the benefit of our smallest patients and their families."

Driving the importance of family-centred care

In 2009 the POPPY Report¹ highlighted the practical and psychological needs of families with premature or sick babies, and detailed how these needs are not being met consistently across neonatal units in the

UK. Caring for a baby's entire family is now widely recognised as a crucial part of their overall clinical care, making a positive contribution to the long-term health and wellbeing of the child. This is acknowledged in the Department of Health Toolkit for High Quality Neonatal Services² which outlines a set of principles for the care of babies born premature and sick. Principle three² focuses on the care of the family, with specific recommendations about the physical, psychological and social needs of the baby and family to be addressed. This includes parents' contact with their baby, their involvement in decision making and their need for information and support. The Toolkit's focus on skin-to-skin (FIGURE 2), feeding and positioning was very welcome, as was recognition of the importance of palliative care pathways and bereavement care.

Family-centred care is also recognised in the NICE Quality Standards for neonatal care³. The standards specifically refer to the parents of babies who are receiving care being supported to be involved in planning and providing care for their baby, and being encouraged to have regular communication with clinical staff throughout the care pathway (FIGURE 3). It also emphasises that mothers should be supported to start and continue breastfeeding, including being supported to express milk.

While it is very welcome that family-centred care has been recognised in these standards, there is still much more to do to make these recommendations a reality. Family-centred care has many direct benefits for premature and sick babies – shorter lengths of stay in hospital, lower behavioural stress levels, fewer



FIGURE 2 Mum being encouraged to do kangaroo care with her baby, UCLH. 2009.

readmissions to hospital and enhanced breastfeeding rates. Family-centred care also reduces family stress and improves parenting confidence, as well as raising staff satisfaction. Ultimately, family-centred care enhances the important early attachment between an infant and their family and results in improved long-term outcomes for both.

With no clinical duties, Bliss Nurses will have time to focus on the needs of the whole family and work with colleagues to ensure the standard of family-centred care is raised throughout the region. The second and third Bliss Nurse posts should be in place by the end of this year.

Creating the network of Bliss Nurses is a core strand of our new five-year strategy and our commitment to drive improvements in neonatal care. It is a significant step for a relatively small charity to take – particularly as we will need to raise an additional £6 million. Much of the charity's ongoing work will now focus around improving family-centred care, not only through Bliss Nurses, but also through the Bliss Baby Charter⁴ standards, our training programme and funding of research.

Expanding activities across the country

We are also planning to greatly increase our local presence across the country. We currently have an office in Scotland and a national network of 90 local support groups and volunteers. However, we know that we need to have much stronger links in some areas. Our work has recently been recognised by the Department of Health and we were one of 12 charities to be awarded a DH Volunteering Fund grant. This will help us to establish at least four more regional offices over the next three years. Their focus will be primarily to increase and enhance the support available to recent parents, from other families with previous experience of having a baby born early or sick. Our network of volunteer groups will double and our aim is to have a family support group available locally for at least every intensive care centre in the country.

Through these new groups we will ensure that our parent literature and support services, such as our new counselling programme for families and our free telephone helpline, are available to every family whose premature or sick baby has been in hospital for at least 24 hours.

Bliss' purpose

We exist to ensure that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and of reaching their full potential.

We believe that:

- All premature and sick babies and their families should have the best possible care and support
- Babies should have the same rights as anyone else
- The voices of babies and families must be heard
- Driving quality and innovation in the NHS will deliver improved care for premature and sick babies and their families
- We achieve more by working together with individuals and organisations
- We must always be able to demonstrate the difference we make to the lives of babies and their families.

We will always act in ways that translate our beliefs into positive change:

- Drawing on our expertise and knowledge we offer guidance and support to anyone who needs us
- Turning our passion for our cause into action
- Inspiring others to share our ambitions
- Listening to people's views and learning from their experiences.

We will also be creating new support mechanisms online and using new mobile platforms.

Fighting for change

There have been many changes in policy for neonatal services in recent years – the Toolkit for High Quality Neonatal Service in England, NICE Quality Standards, the All Wales Neonatal Standards⁵ and the forthcoming Scottish Service Standards for Neonatal Care. I am proud of the active part that Bliss has played in lobbying for these standards and contributing to them. Our challenge going forward is making these standards become a reality.

The impact of the current NHS changes (at the point of writing this article) is unclear for neonatal services, particularly neonatal networks. Our commitment for the future is to keep standing up for neonatal services with Government and to do everything possible to ensure that cuts

within the NHS do not impact on the high level of care that babies so desperately need. We will increasingly act as an 'independent regulator' of services – working to identify what is happening in local services and whether resources are reaching them correctly, raising concerns and reporting back through formal channels and to the regulators if we feel that professional standards are not being supported or patient care is being compromised. This can only be achieved through working in partnership with many others – and as always our campaigning work will be constructive and focused on the best interests of the babies.

Partnership

Bliss owes a great debt to the many hundreds of healthcare professionals and families who we work with every year. Without your support Bliss would not be able to achieve even a fraction of what we can accomplish together.

If you are interested in helping shape Bliss' future work, do please get in touch (contact farrah@bliss.org.uk). In particular we are keen to hear from healthcare professionals interested in working with us on deciding which research and development projects we should fund or being a member of a research advisory board or supporting us in designing new publications or training materials for doctors and nurses.

Our new programme is highly ambitious. We hope that is an ambition that many others will share. It is only through working in partnership, such as with First Touch and St George's on the Family Care Coordinator, that we will be able to begin to deliver on goals.

There is so much more for Bliss to achieve, and I am very excited by our plans for the future. For more information about Bliss' new strategy visit: www.bliss.org.uk/futurestrategy

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