

# Three decades and counting

Bliss 30th Birthday Baby Report



**Bliss**

for babies born too soon,  
too small, too sick

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# Foreword

**I am delighted to introduce this 30th birthday edition of the Bliss Baby Report. It is remarkable how a charity started through a letter in a newspaper has gone from strength to strength, and on to help many thousands of families. It has invested millions of pounds in specialist equipment for hospitals, in training for NHS staff and has gathered around it a massive community of supporters.**

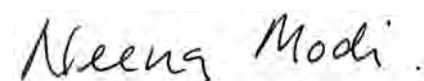
Reading this Report, it is frustrating that the arguments that were being made in 1979 still have to be made by doctors and nurses in 2009. Over 80,000 families call upon Britain's specialist neonatal care services every year when they have a baby who is born early or in need of life-saving treatment. This is a terribly traumatic event for any family to have to cope with. Yet, throughout its history in this country, this vital service has been under-resourced and understaffed, and the rights of the newborn baby under-recognised.

This Report is littered with examples of reports and reviews conducted either by professional organisations or official government bodies that have decried the poor state of the services caring for sick and premature babies. Time and time again, these reports have made their recommendations and raised the hopes of families and those caring for babies in the NHS. Never have their recommendations been fully implemented.

In the meantime, the number of babies being born has increased. The number of babies surviving at early gestations and after grave illnesses has increased. New techniques are being developed and new treatments researched. These make it possible for babies, who previously may not have survived or would have faced a lifetime of long-term difficulties, to go on to lead healthy and happy lives.

After 30 years of fighting to have babies given the standard of care they need and deserve, we believe that 2009 should mark a change in the fortunes of neonatal care. With the NHS Neonatal Taskforce in England, the Welsh Assembly Government deciding to invest additional resources in neonatal care and the Scottish Government committing to implement the recommendations of a neonatal review, there are significant causes for optimism.

In these straitened times, it is imperative that Governments across the UK understand that investing in the services that care for our most vulnerable babies is not just morally the right thing to do. It also makes economic sense. Healthy babies become healthy adults. Investing in the health of the newborn baby is investing in the health of the nation.



**Professor Neena Modi**

Vice President, Royal College of Paediatrics and Child Health  
Former Bliss Fellow, 1982–1983





# Introduction

**Bliss is the only UK charity that helps care for premature and sick babies. We are dedicated to ensuring that more babies not only survive, but also go on to have the best possible quality of life. Bliss provides emotional and practical support for parents and families through what can be a traumatic time in their lives. We also work closely with doctors, nurses and other health professionals to develop solutions to the various problems that exist and to improve care for babies and their families.**

In 2007, approximately 82,000 babies needed to be admitted to hospital for neonatal care. This represents around 11 per cent of all babies born in the UK and means that, on average, a baby is admitted to neonatal care every six minutes. This number is growing, and each year the demand for specialist care for sick and premature babies increases.

## **What is a premature baby?**

The average length of a pregnancy is between 37 and 42 weeks. Any baby who arrives earlier than 37 weeks is known as premature. The majority of premature babies are born just a few days or weeks early. The earlier a baby is born, the more specialised the care they will need.

## **What is neonatal care?**

Neonatal care is the specialist branch of medicine that looks after babies immediately after birth. Many babies admitted to neonatal care will have been born prematurely or born with low birthweight, and will need some extra help until they are strong enough to go home. Others, though bigger and more mature, will have specific medical problems, many of which will require urgent specialist care or surgery.

## **How does neonatal care work?**

Neonatal care is provided in three levels of care in three types of specialist units.

- Special Care is the least intensive level of care, and also the most common. Babies in a Special Care Baby Unit (SCBU) may need to have their breathing and heart rate monitored. They may need to be fed through a tube, be supplied with extra oxygen or treated with blue light for jaundice. Special Care is also where babies who are recovering from more specialist treatment come to get ready to go home.
- High Dependency is the next level of care in terms of intensity. This is for babies who weigh less than 1,000g (2lbs 3oz), are receiving help with their breathing via continuous positive airway pressure (CPAP) or intravenous feeding but who do not fulfil any of the requirements for Intensive Care (see below). A High Dependency unit provides High Dependency as well as Special Care. These units can also provide Intensive Care, but only for short periods.
- Intensive Care is for the most seriously ill babies. Babies in Intensive Care will often be on a ventilator and need constant care to give them the best possible outcome. A Neonatal Intensive Care Unit (NICU) can provide all three levels of care, and some will also have specialist surgery facilities.





A young Bliss campaigner, Richard Evans, who himself benefited from neonatal care, delivers a letter to Number 10 Downing Street in July 1980

# The Bliss story 1979–1989

In August 1979, *The Daily Telegraph* ran a story on the lack of resources for specialist baby units. Dr Donald Bartrop told the newspaper: "The premature baby may live but, unless he receives adequate care, may suffer serious brain damage and multiple handicaps for life... To care for a severely handicapped individual for a 50-year life could cost at least £250,000. A sum like this would cover all annual revenue expenses for optimal perinatal care within a district."

The following week, a letter appeared in *The Daily Telegraph* from Mr Allan Chilvers. The letter suggested setting up a society to raise funds to buy life-saving equipment and to pay for training of specialist staff.



## The Short and Walker Reports<sup>2</sup>

In July 1980 the Social Services and Employment Subcommittee of the Expenditure Committee, chaired by Mrs Renée Short MP, published the findings of their enquiry into neonatal mortality. This was in response to a growing public concern about babies dying unnecessarily or suffering permanent damage. Mortality rates in the UK were falling more slowly than in other developed countries, and there was a wide gap between different socio-economic groups and geographical areas. These problems were predominantly due to a shortage in the provision of resources such as neonatal staff, space and cots. One key recommendation was that care should be regionalised, with a specialist intensive care unit established in each area to care for the sickest babies. The Report echoed the findings of the Walker Report that was published just months earlier and looked at similar issues in Scotland.

Unable to cope with the volume of responses, Mr Chilvers handed over to two mums who had answered his letter. They arranged a meeting of all interested parties on 7 November, and subsequently Bliss (or BLISS – Baby Life Support Systems, as it was then known) was born.<sup>1</sup>

The aim of the charity was, and still is, to give every baby an equal start in life and to ensure that vital equipment and specialist care are available to every baby who needs it.

Within five years, Bliss had increased its reach to almost 60 branches, stretching from Wick to Truro and from Dyfed to Great Yarmouth. Nearly £750,000 had been raised, and donations of specialised neonatal equipment had been made to 82 hospitals.

## An early donation from Bliss



1 Bliss is born



2 The Short and Walker reports are published

1979

1980

1981

1982

1983



Just months after its founding, Bliss campaigners pushed an incubator up Downing Street and delivered a petition asking the Government to consider the recommendations of the Short Report.

The Report called for £25 million to be invested in services caring for sick and premature babies. *The Guardian* newspaper reported at the time: “Mrs Renée Short, Labour MP for Wolverhampton NE, said that the sum involved was a ‘flea-bite’ compared with government spending as a whole, and particularly compared with the defence budget.” Another member of the committee commented: “It is the economics of madness if these proposals aren’t implemented.” Nonetheless, more than ten years later, the recommendations had still not been fully introduced.



Bliss march on Downing Street

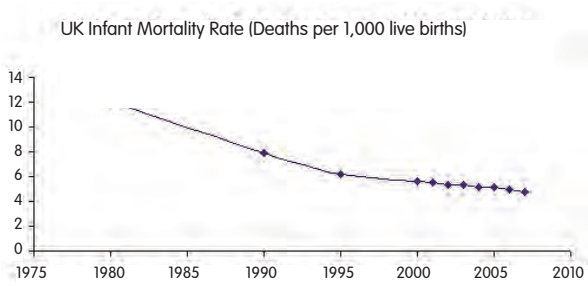
**1983: Blisslink is established**

Blisslink started out as a team of volunteers based in hospitals. They offered practical and emotional support for parents of babies in intensive care. It was started on the principle that parents who had been through the experience wanted to give something back and help others in a similar situation. Today, our ‘Parents 4 Parents’ service continues the tradition!

During this time, Bliss stepped in to fill the gaps that many hospitals were experiencing in their equipment budgets, and attempted to address some of their staff recruitment problems. The first Bliss fellowship was started in 1982. This funded one year of a junior doctor’s training in neonatology at University College Hospital London, with Professor Osmund Reynolds and Dr Jonathan Shaw. In 1984, Bliss funded its first clinical teacher post – responsible for training new neonatal nurses – at St Mary’s Hospital in Portsmouth.

In June 1985, Bliss published the results of its first national survey of neonatal care.<sup>3</sup> It branded services as “inadequate and haphazard”. It found that there was at least a 50 per cent shortfall in the provision of skilled nursing care in some units – based on the British Paediatric Association’s recommendations.

Professor Neil McIntosh, then Consultant Paediatrician at St George’s Hospital in Tooting, told Bliss at the time: “Every week of the year, I have to turn away as many newborn babies requiring intensive care as I can take... My inability to take the infants offered stems primarily from the inadequate number of trained neonatal staff (particularly nurses) in the country as a whole. The already stressful field of neonatal intensive care in this way is heightened, and unwarranted blackmail is used to get staff to spread their expertise even thinner to manage ‘just one more baby’.”



The number of babies dying in the UK has declined steadily over time. In spite of this, the UK’s infant mortality rate is still one of the highest in western Europe. (Source: UNECE Statistical Division Database and NHS Hospital Episode Statistics)

In 1988, the Royal College of Physicians released a report entitled *Medical Care of the Newborn in England and Wales*.<sup>4</sup> This recommended coordinating the care of babies regionally, in what would become known as managed clinical networks.

**3 The 1st Bliss survey is published**

**4 Medical Care of the Newborn in England and Wales Report is released**

1984	1985	1986	1987	1988
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# Life on a neonatal unit 30 years ago

Anne Birkert gave birth to her daughter Felicity on 2 July 1979 at 25 weeks gestation, via emergency caesarean section. Weighing just 11lb 10oz, the consultant hinted to Anne and her husband Peter that Felicity had around a ten per cent chance of a "happy outcome"

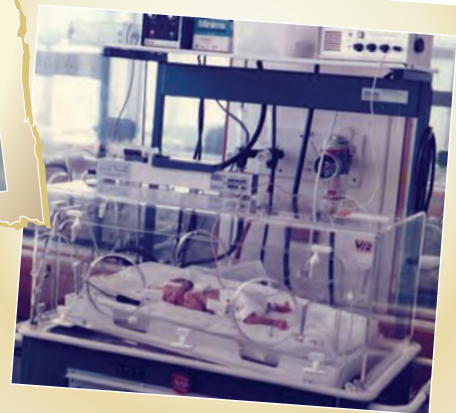


Felicity Birkert at two weeks old, lying on her front, feeding on her mother's milk through a tube

Anne says: "When I came round, Peter wheeled me up to see our baby in the special care baby unit. I was very apprehensive and not even sure I wanted to see her but, as soon as I laid eyes on the tiny, skinny scrap lying under the hot lamp, she was ours... She was long, but with no fat at all. She had several tubes attached to her; staff plucked her from the mattress by putting one hand round her body."

The intensive care unit at New Cross Hospital, Wolverhampton, where Felicity began her fight, accommodated just four babies. Felicity was placed under a hot lamp, with a feeding tube through her nose, containing Anne's expressed breast milk. As Felicity was breathing on her own without a ventilator, Anne and Peter were reassured by the hospital chaplain who baptised Felicity that this was a good sign.

Anne, Peter and their 20-month-old daughter Joanna visited Felicity daily, and felt the support they received from the staff was exceptional. "They fired us up with the need to love her, touch her, talk to her and spend as much time as we could with her, despite her being attached to and surrounded by machinery."



Felicity, incubated at New Cross Hospital in Wolverhampton at two weeks old in July 1979



Anne holds Felicity at six weeks old, along with older sister Joanna, aged 20 months in a 'hot room'

Following six long weeks in intensive care, where Felicity required two blood transfusions and suffered many setbacks, she was moved out of an incubator and into a 'hot' room. Finally, Anne could cuddle and start breastfeeding her baby, which she felt so vital for bonding. At the beginning of September, Felicity reached the final stage – a 'cool' unit, at room temperature. Here she grew and became stronger until she was finally allowed home, weighing 4lb 9oz.

Anne feels fortunate that Felicity's journey through special care was so smooth. She says: "At the time, I heard on the news of twins who were being cared for separately in Oxford and London. I remember thinking how helpless these parents must have felt and how lucky we were to have the dedicated care of staff at Wolverhampton."

"I think how Bliss liaises with families is so important to providing the support they need at a time when they feel so helpless"

While Felicity was fighting for her life, Anne had read Mr Chilvers' letter in *The Daily Telegraph*, and she later decided to become a Bliss member. "I felt I wanted to channel some of our gratitude for our positive outcome, and give something to all the other parents who weren't as fortunate as us," she says. Anne wrote articles for local newsletters and magazines about Bliss and has remained a regular donor throughout the charity's 30 years. "I think how Bliss liaises with families is so important to providing the support they need at a time when they feel so helpless. With the care services as they stand, there is a danger of parents being overlooked and failing to bond with their babies. I feel Bliss has done so much to help these families, and I'm sure will continue to do so."



Felicity with her parents Anne and Peter on her wedding day in January 2005

# The Bliss story 1989–1999

## More babies surviving due to improved treatments

The 1990s heralded two of the most significant improvements in treatment for premature babies. These were the introduction of surfactant and antenatal steroids.

Surfactant is a natural substance produced in the lungs to make breathing easier. It is produced by the body from about 22–24 weeks gestation, but premature babies often don't have enough. Research into the use of surfactant as a medicine started to make serious advances in the early 1990s.

Certain steroids can help to speed up the production of surfactant and help to mature a baby's lungs. Such steroids are now given to women who are about to give birth prematurely.

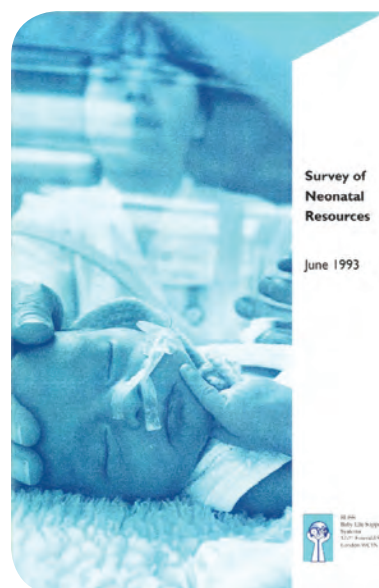
These two advances led to many premature babies surviving and going on to have better outcomes.

In 1990, Bliss gained one of its most significant and long-standing supporters. *Candis* magazine made Bliss one of its sponsored charities – a relationship that still continues today and has raised well over £3 million.

By the 1990s, there had been reports by various bodies on the urgent need to improve care services for sick and premature babies. These mirrored the messages in Bliss' campaigning reports. In 1990, the Clinical Standards Advisory Group (CSAG) was set up to provide independent advice to the Government.<sup>5</sup> They made neonatal care one of their first priorities and released a report in 1993. This echoed earlier reports by recommending that care should be provided in networks and that hospitals should be able to group together to buy the specialist services their local population needs.

Also published in 1993, the Audit Commission Report *Children First* marked the beginning of a series of detailed local audits of hospital services for children in all districts in England and Wales.<sup>5</sup> The Report argued that the service should monitor the outcomes for children who needed neonatal care, so that techniques could be improved and research carried out into better treatments.

Coinciding with the Audit Commission Report in June 1993, Bliss published another national survey of neonatal resources.<sup>5</sup> It found that two-thirds of the equipment in neonatal units had been donated by charities, and at least two units had had everything donated. It also highlighted a worrying shortage of neonatal nurses.



Neonatal care in Scotland Health Committee Report is published

5 Neonatal reports by CSAG, the Audit Commission and Bliss are released

1989	1990	1991	1992	1993
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In 1989 and again in 1999, Bliss was chosen as the partner for the BBC TV *Blue Peter* Charity Appeal. The first, the Aluminium Can Appeal, raised over £375,000 and the second, the New Life Appeal, raised £2.4 million. This money was invested in new equipment and training for specialist staff.

These appeals also helped to spread the public awareness of the underfunding of these vital services and of Bliss' campaign to improve them.

Guidelines setting out how sick and premature babies should be cared for had been produced previously. But these had been criticised for not providing evidence to back up their recommendations. Because of this, few hospitals saw meeting these guidelines as a priority.

In 1996, the British Association of Perinatal Medicine (BAPM) sought to address this by publishing their *Standards for Hospitals Providing Neonatal Care*.<sup>7</sup> These set out the reasons why a nurse caring for a very sick baby should not have to look after another baby at the same time.

### EPICure<sup>6</sup>

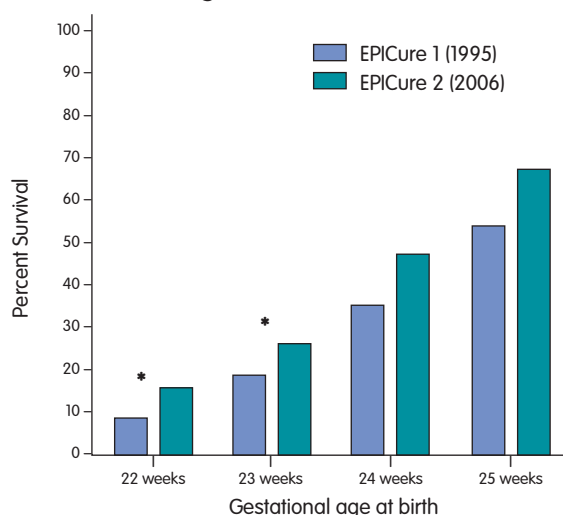
To find out more about the long-term implications for children born prematurely, a team of researchers started the EPICure Study in 1995. This study looked at all babies born before 26 weeks of gestation, and with the help of Bliss aimed to follow them up at four stages throughout their childhood.

Because the techniques used to care for premature babies continued to advance rapidly, it was decided the Study should be repeated in 2006 and the children followed up in the same way.

The two phases of the EPICure Study have helped to shed light on how survival rates for the most premature babies have changed over time.

The chart on the right shows the number of babies surviving at each gestation in the two studies. This is based only on babies who were admitted to neonatal units. It shows gradual improvement for all babies.

**Babies admitted to Intensive Care in England in 1995 and in 2006**



**\*The number of babies surviving at 22 and 23 weeks was so small that the only reliable conclusion to draw is that this is a very rare event.**  
(Source: [www.epicure.ac.uk](http://www.epicure.ac.uk))

**6 First EPICure Study starts**

**7 BAPM publishes clinical standards for neonatal care**



**New Bliss logo is launched**

1994	1995	1996	1997	1998
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# The Bliss story 1999–2009



In 2000, Bliss donated equipment worth over £2 million and spent several hundred thousands of pounds on nurse training, research and supporting families. But at this time, the amount of equipment requested from Bliss far exceeded the amount it could donate.

Bliss donated ten essential incubators to a London hospital in 2000, and ran a campaign at the same time to highlight the extent to which neonatal units across the country were reliant on charity for their equipment. The story made the front page of the *Daily Express* newspaper and was covered in several other national newspapers. Several days later, an additional £6.5 million was announced for neonatal intensive care.<sup>8</sup>

From this point, Bliss gradually began reducing the amount of money it spent on donating equipment to hospitals. Instead, it focused this money on funding more professional training and research into innovative long-term projects aiming to improve the care that babies and their families receive.

## Networks

The role of the managed clinical network is to coordinate the care of mothers and their premature and sick babies across three levels of care in hospitals within a geographic region. This means that a woman who is likely to give birth to a baby needing the most specialised care should be quickly transported to her nearest specialist centre (a neonatal intensive care unit) within the network before she gives birth. The network also coordinates information, training and management of new techniques.

Bliss also took the decision to put more resources into raising the profile of neonatal care with the Government and trying to influence the way neonatal care was delivered. One example of this was our involvement in the review of neonatal intensive care conducted by the Department of Health (DH) in England.<sup>10</sup> This review, published in 2003, again echoed earlier reports in recommending that hospitals providing neonatal care should work together in a managed clinical network. Unlike previous reports, however, this was an official DH publication, and it came with £72 million to assist with the introduction of networks.

The Innovation Fund has funded six research projects so far. These are currently advancing our understanding of issues such as how babies feel and respond to pain, and how to monitor and predict changes in their condition. One of them is also developing a system of simulator training for neonatal staff to practise emergency situations.

## British Association of Perinatal Medicine (BAPM) 2001 Standards<sup>9</sup>

In 2001, BAPM revised their 1996 standards on how neonatal care should be provided. These new standards set out clearly that babies who need intensive care should receive one to one nursing as a minimum. Babies needing high dependency care should be looked after on a nurse to baby ratio of one to two as a minimum, and those in special care one to four.

These standards still apply in 2009, although nursing shortages mean that most hospitals still cannot meet them.

**8 DH announces £6.5 million extra funding**

**9 BAPM publishes new clinical standards for neonatal care**

**10 DH review is released**

1999	2000	2001	2002	2003
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"In 1975, of babies born prematurely with birthweight 1500g or less, about half died in the newborn period (and many others were stillborn). By 1985, this had halved to 1 in 4, and in 1995 had fallen further to 1 in 6 (other babies who previously would have been stillborn are now being born alive)."

### Department of Health, 2003

Following the 2003 review, Bliss decided to try and monitor how the £72 million had been invested. We started a programme of reports looking at how care services were improving.<sup>11</sup> These Baby Reports provide a detailed picture of staff shortages, unnecessary transfers and overcrowded units, as well as examples of how staff manage to provide excellent care in difficult circumstances.

In 2006, the National Audit Office (NAO) announced that they would conduct an audit of the reconfiguration of neonatal services and released their findings in December 2007.<sup>12</sup> This Report, *Caring for Vulnerable Babies*, found that it wasn't possible to account for all of money invested from 2003 because of wide variations in the financial arrangements governing neonatal care. It also found that staff shortages constrained the amount

of care services were able to provide. An accompanying study found that 78 per cent of neonatal units in the UK had to turn babies away in 2006 – eight per cent higher than in 2005.

At the subsequent meeting of the Parliamentary Public Accounts Committee (PAC), the Chief Executive of the NHS David Nicholson was asked to respond to the criticisms of Bliss and the NAO.<sup>13</sup> In response, Mr Nicholson announced that a national taskforce was being assembled to address the various problems that had been identified.

Today, Bliss' Family Support Team provides direct help to over 3,000 families each year, and Bliss distributes over 100,000 publications to families throughout the UK. Our online messageboard has over 2,000 users, and in 2008 the Bliss website had almost 300,000 visits.

### NHS Neonatal Taskforce<sup>13</sup>

This has been the most comprehensive review of neonatal care undertaken in Bliss' lifetime. The quality of care set out in the Taskforce documents is appropriately ambitious and, if implemented, would make a dramatic and lasting improvement to the way babies and their families are cared for.

The Taskforce is chaired by the NHS Medical Director, Professor Sir Bruce Keogh. Its membership has been drawn from a wide range of people including doctors, nurses, commissioners and representatives from the Department of Health, and Bliss.

Bliss believes this is the best opportunity ever to raise neonatal care services up to the standard that sick and premature babies and their families deserve.

## Bliss Baby Reports



Bliss updates its brand identity

11 Bliss Baby Reports begin

12 NAO Report is launched

13 PAC holds session on neonatal care and NHS Neonatal Taskforce is set up

2004	2005	2006	2007	2008	2009
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# Summary

**The services that care for sick and premature babies have been the subject of many reviews and reports over the past 30 years. These have often had common findings and recommendations. Yet none has been fully implemented.**

Bliss believes that 2009 should be the last year that we have to argue that babies have the same right to high quality care as everyone else. The review conducted by the NHS Neonatal Taskforce in England should be the review to end all reviews. Its recommendations must be fully implemented. The Welsh Assembly Government should make the necessary investment for a neonatal network with dedicated transport teams and a neonatal database. In Scotland, the neonatal recommendations of the Maternity Services Action Group should be urgently implemented. In Northern Ireland more work remains to be done to support this vital service.

Regional and local NHS structures will need to dedicate sufficient resources to ensure that problems in both nursing and medical staffing are resolved through long-term recruitment strategies.

## The Bliss vision of the future

- Every baby is treated as an individual and with dignity, respecting their social, developmental and emotional needs, as well as their clinical needs.
- Care decisions are based on the baby's best interest, with parents actively involved as partners in their baby's care.
- Babies receive the nationally recommended level of specialist care in the nearest specialist unit to their family home.
- Units encourage parents to be involved in plans and processes for continuous service improvement, and outcomes of care are benchmarked against local and national standards.
- Parents are informed, guided and supported to help them understand their baby's care processes and feel confident in caring for their baby.
- Breast milk expression and breastfeeding are actively promoted and mothers receive practical support to achieve successful lactation.
- Discharge planning is facilitated and coordinated from admission to discharge home to ensure baby and family have the appropriate care and resources.

In the longer term, Bliss would like to see fewer babies being born prematurely. Having a baby born early is often a traumatic event, it is a dangerous time for the baby and the resources needed to ensure they have the best possible outcome are costly. However, around a third of all premature births happen for no known reason, so further research is urgently needed before this can be a reality.

Other reasons why babies need specialist care at birth are closely linked to the health of the mother. The wide inequalities in health that exist between different communities in the UK must be tackled to make a significant difference to the number of babies who die before their first birthday.

Until that point, Bliss will continue to be there for babies born too soon, too small or too sick and their families.





# References

- The Audit Commission, *Children First*, London: HMSO, 1993
- Bliss, *A Survey of Neonatal Care in the UK*, 1985
- Bliss, *Baby Steps to Better Care*, 2008
- Bliss, *Growing up*, 1985
- Bliss, *Special care for sick babies... choice or chance?*, 2005
- Bliss, *Survey of Neonatal Resources*, 1993
- Bliss, *Too little, too late?*, 2007
- Bliss, *Weigh less, worth less?*, 2006
- British Association of Perinatal Medicine, *Standards for Hospitals Providing Neonatal Intensive and High Dependency Care and categories of babies requiring neonatal care*. 2nd ed., 2001
- British Association of Perinatal Medicine, *Standards for Hospitals Providing Neonatal Intensive Care*, London, 1996
- Chilvers, A, 1979. A reader's response: a plea to save babies' lives. *The Daily Telegraph*, 24 Aug.
- Chorlton, P, 1980. MPs call for £25M spending to stop baby death toll. *The Guardian*, 17 Jul. p1
- Christie, D & Tansey, E. *Origins of neonatal intensive care in the UK*, London, 2001
- Clinical Standards Advisory Group, *Neonatal Intensive Care: Access to and availability of specialist services*, London: HMSO, 1993
- Department of Health, *Neonatal intensive care services - Report of the Department of Health Expert Working Group*, 2003
- Ellis, R, 2000. NHS Puts Babies Lives in Hand of Charities. *Daily Express*, 2 Oct. p1
- EPICure, 2008. *Population based studies of survival and later health status in extremely premature infants*.  
[Online] Available at [www.epicure.ac.uk](http://www.epicure.ac.uk) [Accessed 8 Sept 2009]
- Hallsworth, M, Farrands, A, Wija, J. & Hatziaandreu E. *The provision of neonatal services*, London, 2007
- Healthcare Commission, *Towards better births: A review of maternity services in England*, 2008
- Hope, A, 1979. 'Wanted: More life-saving units to care for babies born too soon'. *The Daily Telegraph*, 17 Aug. p1
- House of Commons Committee of Public Accounts, *Caring for Vulnerable Babies: The reorganisation of neonatal services in England*, London: The Stationery Office, 2008
- House of Commons Health Committee Session 1991-92, *Maternity Services, Second report*, London: HMSO, 1992
- House of Commons Social Services Committee Session 1979-80, *Perinatal and Neonatal Mortality, Second Report*, (Short R, Chairman). London: HMSO, 1980
- National Audit Office, *Caring for Vulnerable Babies*, London: The Stationery Office, 2007
- National Medical Consultative Committee, *Report of the Joint Working Party on Standards of Perinatal Care in Scotland*, (Walker J Chairman), 1980
- Royal College of Physicians, *Medical Care of the Newborn in England and Wales*, 1988
- Scottish Health Service Planning Council, *Neonatal Care in Scotland: Report of the working group set up by the National Medical Consultative Committee of the Scottish Health Service Planning Council*, Stationery Office Books, 1990
- UNECE Statistical Division Database, 2008. *Infant Mortality Rate by Sex, Country and Year*.  
[Online] Available at [www.unece.org.uk](http://www.unece.org.uk) [Accessed 8 Sept 2009]









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**RNID typetalk** 018001 0500 618 140

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**Blisstext** - text messaging advice line. Text 'your name' to 07800 00 8100.

Online parent messageboard [www.blissmessageboard.org.uk](http://www.blissmessageboard.org.uk)

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