

Autumn/Winter 2017

Little Bliss

For the families of babies born premature or sick and Bliss' biggest supporters

"We appreciate and celebrate everything he does." Nicki tells her story

Bliss Baby Cards to mark your baby's milestones. Discount inside!

Help your baby avoid illnesses this winter

Bliss
for babies born premature or sick

Welcome to Little Bliss



If your baby is on a neonatal unit or has recently gone home, Little Bliss is for you. It's full of parents' stories and practical information to support you, however long your baby spends in neonatal care.

If this is the first time you've heard of Bliss, why not visit bliss.org.uk to see what information and support we offer?

Bliss' information and Little Bliss magazine are available thanks to regular donations from generous supporters. If you support Bliss in this way, or any other way, thank you.

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

Caroline Lee-Davey
Chief Executive

About Bliss

Bliss is the leading UK charity for babies born premature or sick. We were founded in 1979 and we exist to give babies the best chance of survival and quality of life by:



Supporting parents to be as involved as possible in care and decision-making for their babies when they are in neonatal care.



Supporting neonatal professionals to deliver high quality care and involve parents actively in their babies' care.



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



Enabling research that can tangibly improve care for babies born premature or sick.

bliss.org.uk

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Little Bliss

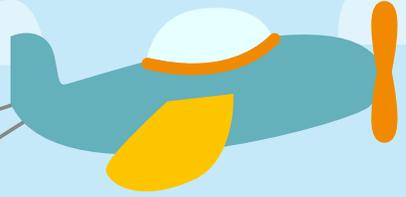
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Celebrate your baby's milestones in neonatal care with our Bliss Baby Cards

Ten beautifully designed cards for you to capture your baby's journey in your own words

Little Bliss readers get 10% off

Use the discount code **LittleBliss39** when buying your cards

Order yours now at
bliss.org.uk/baby-cards



Inspired by baby Ben

Simon Scorer works for the Bank of England and last year he nominated Bliss to benefit from an auction of new polymer £5 notes which resulted in a donation of £64,000 towards our work. Here, Simon explains how his son's neonatal journey inspired this generous support.

Like most expectant parents, Simon and Vicky were eagerly awaiting the arrival of their son Ben. Vicky's pregnancy had been straightforward, so when Ben was born early at 26 weeks of pregnancy weighing 11b 13oz, it was a huge shock to the family.

Simon said: "I felt so helpless in those first moments. I was scared to see him because I was afraid he wouldn't survive. I was allowed to touch him briefly for the first time, before he was put in an incubator and taken to the neonatal intensive care unit (NICU). He looked so tiny and vulnerable.

"Suddenly, Vicky and I were on our own but without our baby. It was surreal. Everything went so quickly and it was difficult to comprehend that we were now parents."

"Vicky was amazing throughout and it's a great comfort to know that Ben was, and is, being looked after by such a great mum"

Later that afternoon, Ben was transferred to the NICU at the Luton and Dunstable Hospital for more

intensive care. Soon afterwards they discovered that he had suffered a serious brain haemorrhage. Simon and Vicky were told the impact of the bleed would not be known for months or even years.

"This was devastating news, and it was difficult not to think about all the challenges it may bring down the road, but we tried to focus on the positive things," Simon said.

"For the first week we stayed in a small room next to the NICU. After that we moved back home and 'commuted' to the hospital every day. No matter how long we stayed with Ben we always felt incredibly guilty whenever we weren't there."

During his stay at Luton, Ben suffered from chronic lung disease, jaundice and required nine blood transfusions. He also needed surgery for patent ductus arteriosus (PDA), a common heart condition in babies in which a duct just outside the heart does not close as expected in the first few



Simon with Ben aged one month



Ben, shortly after he was born at 26 weeks



Ben in the neonatal unit, one month old



Ben at five months with mum Vicky

days of life (**for more information visit bliss.org.uk/patent-ductus**).

“I was amazed by the care Ben received and the staff were so supportive. Not just in taking care of Ben, but also getting us involved and paying attention to how we were coping.

“We found the material Bliss produces to be an invaluable help”

“We found the material Bliss produces for parents to be an invaluable help – not only did it help us to understand and process all the things that were happening to Ben, but it helped us explain things to Ben’s grandparents and other family members who were naturally keen to understand what was happening. Being able to refer to an approachable, reliable and comprehensive source of information was a huge help to me and Vicky.

“Going back to work was tough. It was difficult to think about anything other than Ben, and to be so far away from him and Vicky. But my work was incredibly supportive, allowing me to work from home a lot which made the daily hospital visits much easier. It was physically and emotionally draining, but we got ourselves into a routine.

“It was clearly a difficult time for Vicky too. She was so focused on Ben that it was easy to forget what she’d been through herself. She was amazing throughout and it’s a great comfort to know that Ben was, and is, being looked after by such a great mum.”

As his condition improved, Ben was transferred back to the high dependency unit in Stevenage where he was born.

“We were shown how to bottle feed him, how to use home oxygen tanks and tubes, how to bathe him, and we had a lesson in resuscitating a baby. We roomed in for a few nights and then after 12 weeks in hospital we were able to take him home.

“You have to try to take each day as it comes and not look too far ahead”

“Bringing Ben home was daunting at first. Especially since he was coming home on oxygen. Again the Bliss leaflet on home oxygen was very useful and we soon got used to it.

“It was great to finally have Ben home and be able to do things as a family. There were points during our NICU journey we thought we might never be able to. Just simple things like a walk round the park with Ben in the pram meant the world to us.

“Some advice we were given at the time was that worrying doesn’t stop the bad things from happening but it does stop you from enjoying the good. You just have to try to take each day as it comes and not look too far ahead, trying to enjoy the little moments and successes when you can – kangaroo

cuddles, gaining weight, moving out of the incubator, coming off oxygen.”

“As things began to settle down I decided I wanted to do something to support Bliss. I completed the Royal Parks Half Marathon raising over £1,200 for Bliss and I successfully nominated Bliss to receive a donation of £64,000 from an auction of new polymer £5 notes by the Bank of England.

“Ben still has some issues using his left-hand side as a result of the brain haemorrhage and has regular sessions with a physiotherapist and occupational therapist. But as he comes up to his first birthday it’s amazing how far he’s come. He has grown into a very happy little boy and we couldn’t be more proud.”

**Could you or your company help to support babies in neonatal care?
Find out more at
bliss.org.uk/company-support**



Vicky and Ben (aged 10 months) at the zoo



Simon, Vicky and Ben, aged 11 months

Bake for Bliss

Help raise money for premature and sick babies by hosting your very own bake sale

Sign up now to receive your FREE fundraising pack

bliss.org.uk/bake



Look at them now

Every issue we follow the remarkable and often miraculous journey of a baby born premature or sick. In this issue we meet Alejandro, who was born at 24 weeks of pregnancy.



Alejandro was born in 2006 at Chelsea and Westminster Hospital. He was 24+2 weeks' gestation and weighed just 645g.



Alejandro was a fighter from birth. He battled chronic lung disease, a heart condition and NEC (a serious illness where tissues in the intestine become inflamed and begin to die) throughout his stay in NICU.*

*For more information on these conditions and many others, visit bliss.org.uk/medical-conditions-and-procedures



Alejandro was diagnosed with retinopathy of prematurity (an eye disease that can occur in premature babies). Surgery failed on both eyes and the surgeon told his parents "your child is blind".



Alejandro stayed in NICU for five and a half months. His mum Gigi said: "It elicited a range of emotions – upset, angry, confused, trauma, joy, panic, happiness, fear. It felt like we were on an endless emotional roller coaster."



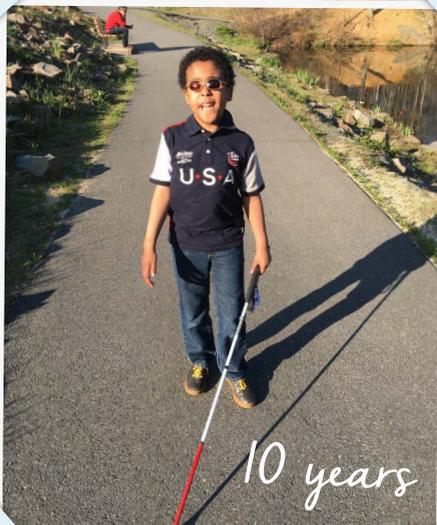
Alejandro went home one and a half months after his due date. Gigi said: "We were ecstatic but nervous and wondered if we could really take care of this tiny human without the constant support of the NICU staff."



The family moved to the USA when Alejandro was two years old to be closer to his eye surgery team. He started at a pre-school where half the students were blind and the other half fully sighted. He loved the teachers and friends he made there.



Alejandro was growing into a happy child. He started learning pre-Braille and how to use a cane. Gigi said: "Despite his complex start in life he has a great personality and an infectious giggle."



Alejandro now attends a mainstream school. He plays the drums, piano and violin and loves to read Braille books. He also speaks fluent Spanish. Gigi said: "We always say that he's a gift from heaven. We want him to stay happy and be confident in using all the gifts God's given him."

Read this story in full at
bliss.org.uk/gigis-story

The biggest baby on the ward: what NICU is like for full-term parents



Hugo and Lyn's first skin-to-skin cuddle

More than half of the babies who spend time on the neonatal unit are born full term but sick. Lyn Swannell shares the story of her son Hugo who faced challenges with his breathing after birth.

"My little boy Hugo was born at 38+6 weeks of pregnancy via c-section. Initially everything was okay but within an hour a nurse quickly grabbed him from me, saying she was unhappy with his skin colour.

“What I thought was just going to be a quick check-up ended up being the start of every parent’s nightmare.”

Hugo was taken to the special care unit and given oxygen but this did not help and he was soon put on a machine to help with his oxygen levels known as continuous positive airway pressure (CPAP).

“Seeing my baby in the NICU was terrifying. It was so noisy...it was dark inside and there were lots of tiny babies”

“That first night was really difficult and although the midwives put me in a private room it was hard hearing all the other babies and wishing I had my little boy with me.

“The next day the news wasn’t any better. They had done an X-ray which showed Hugo’s lungs weren’t inflating

properly and there were signs that he may have an infection.”

Hugo was then transferred to Birmingham Heartlands Hospital for more intensive care.

“Seeing my baby in the NICU was terrifying. It was so noisy - machines beeped constantly and alarms went off. It was dark inside and there were lots of tiny babies.

“The next morning when we got to his incubator his breathing rate was worse and he was still on CPAP. It was at this point I just could not stop crying. The nurse told us he hadn’t reacted well to being taken off the CPAP, his infection was getting worse and he wasn’t responding to the antibiotics he was on.

“It felt like being hit by a truck. I couldn’t understand how this was happening. He was full term, not premature like all the other babies in the room, yet he was really poorly and I couldn’t do anything about it. I felt completely



Hugo needing ventilation in the intensive care unit



Hugo off the ventilator three days later

redundant as his mum. I couldn't hold him and I wasn't even able to express milk at this point.

"The decision was made to put Hugo on a ventilator – which terrified me – and he had a head scan and lumbar puncture (taking fluid from the spine) to try to determine his infection. Our nurse was lovely and reassured us not to see the ventilator as a step backwards but as a way of giving him a break. He was working so hard to breathe and it was exhausting him."

"He was full term, not premature like all the other babies in the room, yet he was really poorly and I couldn't do anything about it"

"I felt completely redundant as his mum. I couldn't hold him and I wasn't even able to express milk"

The results of Hugo's lumbar puncture and head scan looked good and the ventilator was stabilising his breathing. Doctors also changed his antibiotics and things began to improve.

Eventually Hugo's breathing rate was stable enough that the ventilator could be removed.

"Five days later I got to hold him. When the nurse gave him to me for skin-to-skin it was the best feeling in the world, maybe even better than when he was born. I was still scared of the wires but it was an hour of cuddles I had been waiting for.

"Hugo went from strength to strength. He even pulled out his own feeding tube as if he'd had enough of hospital and wanted to hurry things up. We got the all clear for a discharge ten days after he was born. Although we were desperate to get him home it was strange to think that it would just be us, with no doctors or nurses.

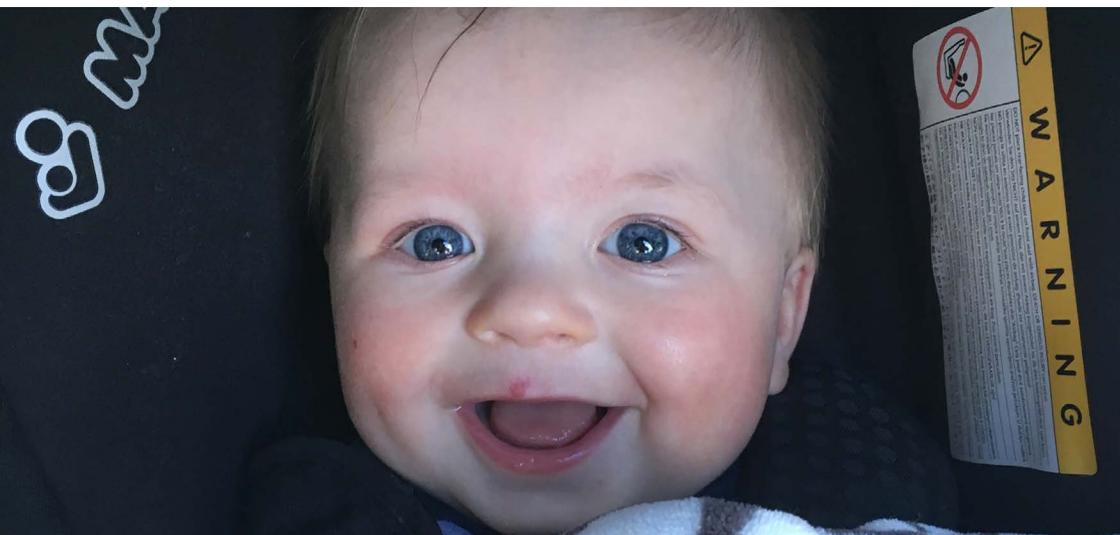
"The NICU had become our safe place where there was always someone to help and it was scary to step away from that.

"I'd met so many amazing people – other mums that had been there for months, Bliss volunteers who had been through the NICU themselves, nurses working tirelessly, and doctors who really took the time to explain what was happening to our baby. It's a place that will always stick with me, an experience you can't explain to people who haven't seen inside the world of neonatal care."

"It's a place that will always stick with me, an experience you can't explain to people who haven't seen inside the world of neonatal care"

Hugo's now a healthy and happy seven-month-old who only needs one more check-up. Lyn said: "You would never know what a rocky start he had and I can't stop cuddling him."

If your baby has spent time in neonatal care why not call or email our trained volunteers for support on 0808 801 0322 or hello@bliss.org.uk



Hugo at seven months



Our journey to parenthood

Please be aware that the following article is about the birth of twins where only one survived

Nicki and her husband Kevin were in complete shock when they learnt that they were expecting twins at their 12 week scan. The pair immediately set about preparing for early labour but they never expected that their babies would arrive quite as soon as they did.

Labour began on Boxing Day 2015 and the following morning, at 23 weeks of pregnancy, Nicki gave birth to twin boys Henry and Archie, each weighing 1lb 2oz.

"We were told it would be a miracle if either baby survived, but at first they both did pretty well," Nicki said.

"The neonatal journey was difficult, but my husband and I were both strangely comforted by all the equipment. We are both quite technologically minded and knew that the machines were necessary to ensure the health of our babies."

Nicki felt hugely relieved that both Henry and Archie had survived the birth but unfortunately things soon took a turn for the worse.

"We were a little naïve in the beginning, thinking that the equipment and doctors could fix anything and unfortunately we were wrong," said Nicki.

At two days old, nothing more could be done to save Archie. His parents had him blessed and said goodbye while holding him in their arms. Anxiety for his brother then took hold of the couple.

"From then on we were in a constant state of worry for Henry, not knowing what the next day, hour or minute would hold for him. We'd dare not

think more than a few hours into the future as things could change so quickly." Nicki spent every day on the unit with Henry, feeling lost if she was anywhere but the hospital. She expressed milk by his side and read him bedtime stories to bring some normality to their routine.

"We were in a constant state of worry for Henry... We'd dare not think more than a few hours into the future"

Henry continued to fight on. He survived sepsis, three infections and twelve blood transfusions. He was placed on morphine for a long time, needed a ventilator to help him breathe and was given steroids for his lungs. Although the journey was a roller coaster, Henry went from strength to strength.

At the end of January, Nicki was able to cuddle him for the first time. His parents



Henry at six days



Henry on CPAP



Going home after 114 days



Kangaroo cuddles at home

were able to hold him for a magical 15 minutes each.

By March Henry had become more stable and Nicki and Kevin were finally able to hold Archie's funeral.

"Although it was a sad day, the service was just as we wanted. Some of the nurses and consultants from the unit even came along, which was very touching."

Talking about Archie often and not keeping her feelings bottled up has helped Nicki cope with losing Archie.

"If you need to cry, it's best just to let it out," she said. "Don't put too much pressure on your partner to react the same way as you – different people deal with grief in different ways. What seems like an unrelated emotional outburst can often be grief-related so be sure to talk to each other about everything."

The experience of having premature twins was a difficult one, but Nicki says that there were joyous moments along the way including celebrating Henry's milestones, seeing in the new year by her son's side and feeling like a part of a family on the unit.

"We are both happy with the parents we have become as a result of our journey. We appreciate and celebrate everything Henry does"

Nicki says that establishing a routine and being involved in Henry's care also helped her and Kevin.

"Having a bedtime routine for Henry helped to bring normality to the situation and for us this involved

reading him a bedtime story every night (and still does!) Later in his journey, washing him, changing his baby-grow and laying him on his tummy were also important to us. I'd recommend other parents find a routine and a sense of normal that works for them.

"The staff at the hospital were there for all the ups and downs, offering shoulders to cry on and congratulatory hugs. So many nurses came to visit us while rooming-in to say goodbye, which was very touching."

Finally, at 114 days old, Henry was able to leave the hospital and go home with his mum and dad for the first time.

Both Nicki and Kevin said they were grateful for the support that Bliss gave them along their journey.

"Bliss is an excellent charity that gives information to families and supports very important research," Nicki said.

"Bliss was also a useful resource before giving birth as we had looked into

prematurity in preparation as we knew it was a risk with twins. The information was so handy. Henry is now a very lively and energetic 20-month-old who enjoys toddling around. He is a social little boy who loves attending music-related baby and toddler groups and swimming lessons. Henry still loves books and Nicki has written one for the parents of premature babies to read to them.

Nicki said: "Although I'd never want Henry or anyone else to go through the experience, we are both happy with the parents we have become as a result of our journey. We appreciate and celebrate everything he does."

"We're so pleased that Henry is developing so well with no signs of developmental delays or issues resulting from his extreme prematurity."

If you have been affected by the issues in this article and would like to speak to someone, please call or email the Bliss helpline on 0808 801 0322 or hello@bliss.org.uk



Henry as a happy and healthy toddler



Henry taking part in a Bliss Little Heroes Walk

If doctors and nurses take care of babies, how does Bliss make a difference?

You may be wondering how supporting Bliss can help improve care for babies on neonatal units. What you may not know is that in the background Bliss is working alongside healthcare professionals to improve the care babies receive through the Bliss Baby Charter. Here, Nicola Frith, Senior Project Officer at Bliss, tells us more about it.

Q: Nicola, what is your role at Bliss?

A: I support neonatal units across the UK to improve the quality of the family-centred care they deliver.

Family-centred care means helping parents to be involved in their baby's care and in making decisions about them. Research shows that when parents can provide hands-on care in this way, babies have better outcomes.¹

Q: How does the Bliss Baby Charter improve care on neonatal units?

A: The Baby Charter is a list of standards covering things such

as emotional support, how parents are consulted in decisions regarding their baby and what facilities the unit should have to enable parents to be involved in their baby's care. The Baby Charter shows what great family-centred care looks like and gives recommendations and support for neonatal units to introduce lasting improvements.

Q: What kinds of changes have been made because of the Baby Charter?

A: Staff have been trained to offer counselling to support families on the unit. Units have introduced headphones for parents so that they cannot hear medical updates about other babies during ward rounds but they can remain in the room with their baby. Video diaries have been introduced to share a baby's progress and apps

¹POPPY steering group (2009) *Family-centred care in neonatal units: A summary of research and recommendations from the POPPY project*. View at bliss.org.uk/POPPY_Family_centred_care

Bliss

for babies born



have been created which provide key information such as hospital parking costs and visiting times. One thing is for sure: staff taking part in the Baby Charter are continually striving to make changes that improve the care of babies and the experience of families.

Q: If family-centred care is so beneficial for babies, why don't all units have this approach already?

A: All units aim to deliver a family-centred approach to care but the Baby Charter ensures that this care is of a consistent high quality among all neonatal units, and that babies are benefitting from the same care in every unit. This is especially important when babies are being transferred between units.

Q: What do units think of the Baby Charter?

A: The Baby Charter is very popular, with 138 out of 195 units now taking

part. Unit staff have told us they really value Bliss' support through the workshops and training we give. But while Bliss facilitates change, the teams on the units make the change happen!

Q: How long does it take for a unit to become accredited?

A: On average it takes two years for a unit to become accredited, although this does vary. There are several audits in which units grade themselves from red, amber to green. When a unit is working at the recommended level Bliss will assess them to see if they are ready for accreditation. Both health professionals and parents help with the assessment.

Q: If a unit is not accredited, does it mean the care at that unit is not as good?

A: If a unit is accredited it means that they are delivering exceptional family-centred care in line with the

Baby Charter standards. But this does not mean that units that haven't been accredited with us aren't delivering a good service. These units may not be taking part in our Baby Charter or they may be at an earlier stage in their Baby Charter journey.

Q: How can you find out if a unit is taking part in the Baby Charter?

A: You can view our map to see if your unit is taking part in the charter, at bliss.org.uk/bliss-baby-charter-map

What parents say about the Bliss Baby Charter

"The hospital caring for Miles gained Bliss accreditation while he was there. Family involvement in care and decision-making, including positive touch, changing clothes and nappies, bathing and feeding was of paramount importance and Bliss standards assisted the hospital in being able to deliver this.

"This allowed us to feel closer to our baby, more confident to ask questions and be involved in decisions regarding his care, and ultimately on the day it came to us leaving for home we felt confident in looking after him."

Victoria Gamble, mum to Miles, born at 30 weeks

Did you know...

Over 70% of neonatal units are now working towards the Bliss Baby Charter standard of excellence, which drives up and maintains the quality of care given to premature and sick babies.



Of these units, many have already made improvements and **three units** are now Bliss Baby Charter accredited – setting the standard for exceptional care for babies.



Last year Bliss also trained health professionals from **a third** of UK neonatal units.

Online only!

Watch our video about how to get involved in your baby's hospital care and the benefits of family-centred care at bliss.org.uk/family-centred-care

an early arrival?



our range of
premature baby clothes
start from 3lbs/1.4kg

free next day delivery on all premature clothing

terms and conditions apply

mothercare
welcome to the club

mothercare.com

You asked, we answered...

Common infectious illnesses

In this issue of Little Bliss we address a common worry by helping you reduce your baby's risk of illness after you have left the unit.



Use disposable tissues

Throwing away tissues helps to reduce the risk of infections on surfaces.



Go smoke free

Babies and children are more vulnerable to the effects, and premature babies and those with fragile lungs can be seriously affected by cigarette smoke. Even smoke on furniture, clothes, hair and in the baby's general environment will still have a negative impact on their health, even if you never smoke around your child.



Keep your baby's environment clean

Clean toys, highchairs and worktops regularly, as germs can live for up to 48 hours on surfaces. Make sure any antibacterial cleaners are safe to use around children and keep them far out of reach.



Avoid people who are unwell

If your baby is at a higher risk, you should try to avoid contact with other adults and children with cold-like symptoms (such as a runny nose, sneezing or feeling generally unwell) or who have had a stomach upset.



Look, don't touch

If someone asks or tries to touch your baby, but you are worried about their risk of infection, don't be afraid to ask them to look instead. This will help to reduce the number of possible infections for your baby.



Wash your hands thoroughly

Washing your hands often is really important in the fight against infections. Visit the link below to see how you should wash your hands to best reduce the risk.

Visit bliss.org.uk/winter for more information



Also online - weaning your premature baby.

Find out how to tell when your baby is ready for solid foods. Watch our new video and read more at bliss.org.uk/weaning

Parent-to-parent: how to ask for help

When your baby is in neonatal care you can experience a whole range of emotions. It's important to remember that you can, and should, ask for help if you need it. Here we share other parents tips on asking for help.



I don't have anyone
I can speak to who
will understand

(Anonymous) "When you are suddenly thrust into this terrifying world it is so overwhelming. Talking to a Bliss Champion (volunteer) helped us break down the situation and it was a huge help talking to someone who wasn't using medical jargon."

Ask the staff at your unit if they have a Bliss Champion and when they visit.



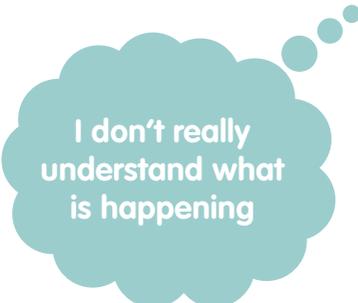
I've got so much
on my plate, I feel
really overwhelmed.

It's okay to accept help – in fact, those around you may be wondering what they can do for you. You could ask for help running errands or babysitting other children, help with keeping others updated about your baby's progress, or you could ask for space to be alone with your baby – many parents need this.

Sarah-Jayne says: "Ask friends and family for practical help. You don't have to do it all."

Holly says: "Each time someone visited we felt drained. It zapped our energy ensuring they followed all of the rules. We spent a lot of time feeling guilty about turning down people for visiting but we needed the space."

Read about eight ways others can lend a hand at [bliss.org.uk/eight-ways-to-help-little-bliss](https://www.bliss.org.uk/eight-ways-to-help-little-bliss)



I don't really understand what is happening

It's okay to ask health professionals the same question again or to ask them to use other words to explain something. If you're not sure what to ask but you'd like to understand your baby's situation better, you could ask what your baby's medications are called and what they are used for, why your baby does certain things, how to make your baby most comfortable or if you can check their notes or call the hospital at any time.

Sarah says: "Ask one of the nurses involved in the baby's care to explain things to you. The nurses at my unit were so good at repeating themselves as we weren't able to absorb much information in the early days. They had so much patience with us."



I am finding it hard to cope

It's okay to need a bit of emotional support when your baby is in hospital, and there's lots of help available. You can speak to someone from Bliss by calling **0808 801 0322** or emailing **hello@bliss.org.uk**. We can also connect you to interpreters speaking more than 200 languages.

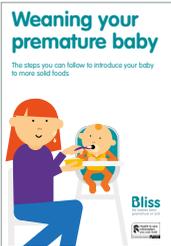
Mark says: "You can lose the plot and sob uncontrollably – that's fine and normal."

If you need bereavement support, Sands is here for you as well. You can speak to someone by calling **0808 164 3332** or emailing **helpline@uk-sands.org.uk**

To find out more about the support above and for an extensive list of useful organisations, visit bliss.org.uk/useful-organisations

Bliss' information for parents

Bliss has more information available for parents of babies born premature or sick



Weaning your premature baby

Our online information about weaning a premature baby gives tips on parents' common questions. Visit bliss.org.uk/weaning to read more and to watch our video. You can also ask your health professional for one of our weaning info cards.



Bliss family handbook and Your special care baby

Parents often feel overwhelmed when they first come into the neonatal unit. The *Bliss family handbook* and *Your special care baby* provide information about life on the unit and the care of premature and sick babies.



You can read what to expect from intensive and high dependency care in the *Bliss family handbook* and from special care *Your special care baby*.

Ask your health professional or order your copy from our shop at bliss.org.uk/shop



Skin-to-skin with your premature baby

Read about the benefits of skin-to-skin with your baby, and how you can feel comfortable holding them.

Ask your health professional or order your copy from our shop at bliss.org.uk/shop

Bliss updates

Bliss launches new research fund

Bliss is delighted to announce the launch of a new fund for neonatal research projects.

The fund, which will be available to researchers across the UK, will provide grants to carry out research to improve the lives of babies born premature or sick.

We worked closely with a panel of parents, health professionals and an adult who was born prematurely, as well as experts in the field, to identify the key research questions. We also looked at those areas which need further research to identify our priorities.

“It’s incredibly important that neonatal research is funded and treatments for the most vulnerable babies are based on strong evidence”

Caroline Lee-Davey, Chief Executive of Bliss, said: “We are excited to welcome funding applications from researchers. It’s incredibly important that neonatal research is funded and treatments for the most vulnerable babies are based on strong evidence.

“We have put a lot of care into choosing our priority areas and we believe funding research into these areas will help to give premature and sick babies the best chance of survival and quality of life.”

For more information please visit bliss.org.uk/research

We want to invest in neonatal research for years to come. Help to build this future by setting up a regular donation to Bliss at bliss.org.uk/regular-gift

App gives parents daily updates on their baby

A new project between Bliss and researchers from Imperial College London will give parents access to daily information about their baby, which is currently only available to health professionals.

The project, called Better Use of Data to improve parent Satisfaction (BUDS),

aims to see if parents can feel more involved in their baby's care through the use of an app. It will give parents a daily summary of the information that is entered by doctors and nurses on electronic patient records (EPR). This includes details of a baby's weight, breathing support, milk taken and other key information.

Through the BUDS project parents will be able to contribute towards the type of information the app will provide. We are talking with parents to understand:

1. How they were given information on the unit
2. What they would have liked to be told
3. How the information available electronically fits with what they want to know

The app will be trialled on the neonatal unit at Chelsea and Westminster Hospital to see if it increases parent satisfaction with communication, care and involvement.

For more information please visit the BUDS Facebook (BUDSProject) or Twitter pages (@BUDS_study) or visit neoePOCH.com

Pampers and Bliss donate smallest ever nappy to hospitals

Pampers has developed the smallest ever nappy, and with Bliss' help has donated them to neonatal units across the UK.

The nappy (Preemie Protection Size P3) is three sizes smaller than a regular newborn nappy and is suitable for babies weighing as little as 1.8lb (800g).

“The nappy change is a way for parents to take the lead in their baby's hospital care”

Regular newborn nappies can push smaller babies' legs apart, preventing their hips and legs from resting comfortably and hindering their development. The new nappies from Pampers have been designed with nurses to meet the needs of premature babies and to minimise this disruption, improving babies' sleep, positioning and medical care.

Caroline Lee-Davey, Chief Executive of Bliss, said: “The nappy change is a way for parents to take the lead in their baby's hospital care, and nappies that are fit for purpose will make this so much easier.”

Parents on Facebook were also pleased to hear about the new nappy. One said: "Well done Bliss and well done Pampers. The previous size exclusive to hospitals was still too big for my little boy and size 0 was way too big when we got him home as well. I am so pleased that things like this are continually being looked at."

The new nappies are being rolled out to hospitals across the UK. If you haven't seen them on your unit please ask staff to contact Pampers at pampers.preemies@sykes.com



Bliss Baby Cards celebrate babies' milestones

Bliss has launched a new range of cards celebrating the milestones of babies in neonatal care, thanks to a successful crowdfunding campaign.

Bliss Baby Cards went on sale in July and include milestones such as leaving the incubator, having a first cuddle and going home.

Thank you to all those who generously donated to get the project off the ground. The cards can now be purchased at bliss.org.uk/shop

To celebrate the launch of Bliss Baby Cards, we're giving Little Bliss readers 10% off their first order. Use the discount code **LittleBliss39** when buying your cards.

Bliss chosen as Mothercare Charity of the Year

Mothercare has named Bliss as its Charity of the Year for 2017-18.

Staff at Mothercare voted to support Bliss this year, moved by our mission to ensure every baby born premature or sick receives the best care.

Mothercare will be donating proceeds from sales made in its staff shop to Bliss, as well as taking part in employee-led fundraising activities such as a golf day and bake sales.

Bliss already has a longstanding relationship with Mothercare, having worked together with neonatal nurses and new parents to develop their premature baby clothing range (from 3lb) in 2011. The company also offers free home delivery on premature baby clothing for parents caught off-guard by the sudden arrival of their baby.

“Bliss plays such an important role in the lives of parents and babies”

Mark Newton-Jones, Chief Executive of Mothercare, said: “We are delighted to be in partnership with Bliss, a charity that plays such an important role in the lives of parents and babies, providing invaluable support to families at such an important time.”

Caroline Lee-Davey, Chief Executive of Bliss, said: “It is only thanks to the generosity of supporters like Mothercare and its employees that we can make sure that every baby gets the best care. I am thrilled that we’ve been chosen as their Charity of the Year and I am really looking forward to building this partnership with them.”



Special tribute to Bliss' first president

Professor Os Reynolds, who died this year aged 83, was one of the founding fathers of neonatal medicine and an instrumental figure in the early years of Bliss.

Professor Reynolds – Os, as he was known – played a pioneering role in developing modern ventilation techniques for premature babies with breathing difficulties, dramatically increasing survival rates, as well as undertaking groundbreaking research into neonatal brain injury.

Os was also a keen supporter of Bliss from our foundation in 1979. He led our first Medical Advisory Panel and then became our first President in 1983, holding this position until 1997, just after his retirement.

Susanna Cheal OBE, Chair of Bliss' founding trustees, said: "Os helped us frame our mission to give every baby an equal start in life by ensuring that no baby died, or became disabled at birth, through lack of equipment or skilled care during the critical first moments and weeks of life. With great commitment and enthusiasm – and applying his comprehensive knowledge of neonatal care – he led our Medical Advisory Panel to safeguard our early

work in redressing the inequality of access to proper neonatal support.

"This was done through safe equipment donations to the hospitals considered to be in most need, supporting medical and nurse training, and offering support to parents in shock and dealing with a sick baby.

"Os was a guiding light to Bliss' pioneers... We will be forever in his debt"

"Os was a guiding light to Bliss' pioneers. We are keenly aware of his contribution to neonatal medicine and his founding importance to Bliss. His counsel and support were always freely given and we, along with many babies and their families, will be forever in his debt."



Professor Os Reynolds

Top fundraising picks

November 2017 to April 2018

There are lots of fun and exciting ways to fundraise for Bliss and support our work for premature and sick babies. From cake sales to climbing mountains, we've got an event for you. See our full events calendar at bliss.org.uk/events



Runs

Brighton Marathon 15 April

With a stunning backdrop of the sea, the Brighton Marathon is one of the UK's favourite runs

London Landmarks Half 25 March

London's brand new half marathon through Westminster and the City

Edinburgh Marathon Festival 26/27 May

Scotland's largest running festival with seven races and more than 30,000 runners expected to take part



Challenges

Isle of Wight Challenge 5/6 May

With white cliffs, sandy beaches and stunning views. Walk, jog or run 100k, 50k or 25k

Skydive

Various dates and locations

London to Brighton Challenge 26/27 May

Whether you're new to endurance events or a marathon runner looking to up the distance, the journey will be amazing. There's 100k, 50k or 25k and you can do it alone or as a team



Bliss events

Bliss Little Lights Walk November/December

Host your own lantern-lit sponsored walk or join our flagship London walk to mark World Prematurity Day

Bake for Bliss

We need lots of you to host bake sales and raise some dough for Bliss! Get involved and pick a date that suits you

"My skydive was absolutely amazing! I wore my Bliss T-shirt and had a lot of people commenting on it which made me feel amazing for raising money for such a wonderful charity"



Overseas

Inca Trail to Machu Picchu

21-30 April

1-10 September

Trek this breathtakingly beautiful route through valleys and high passes in Peru, scattered with Inca ruins

Mount Kilimanjaro

23 January - 4 February

Climb the highest freestanding mountain in the world!

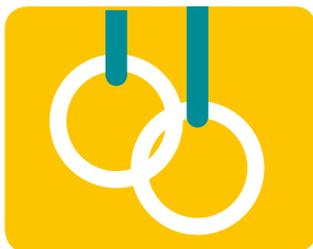


Cycling

Bike for Bliss

Set your own challenge. Anytime, anywhere, any distance

A few ideas: Coast to Coast, London to Brighton, Dragon Ride



Obstacle races

Tough Mudder

A 10-12 mile course designed to test strength, stamina and mental grit

The Spartan Race series

Simply the world's toughest obstacle race

Gung-Ho!

A 5k inflatable obstacle race – what more is there to say!

Hold your own events

If you want to organise your own event we can send you balloons, stickers, posters, T-shirts and collection tins

Why not...

- Throw a Bliss party
- Have a stall at a local fair

Request one of our fundraising packs for more inspiration by emailing events@bliss.org.uk

Why fundraise for Bliss?

Fundraising for Bliss can make a difference to babies' lives by helping to improve the care they receive and the support their family has access to.

Raising money helps us to support neonatal research, which can improve care for babies in future.

As Bliss is the leading national charity for premature and sick babies, raising money for us also means you're helping to champion babies' voices at a national level, raising the profile of babies in neonatal care and giving them the attention and support they deserve.

Read about [why Bliss is needed](#) and [about our work at \[bliss.org.uk/our-work\]\(http://bliss.org.uk/our-work\)](#)



Bliss is here for you

Information and support

Find information about premature or sick babies, neonatal care and much more at bliss.org.uk

Peer support

Speak to other families with a baby in neonatal care on the Bliss/Netmums forum
bliss.org.uk/Netmums-forum

Support via phone or email

For information or emotional support call or email the Bliss helpline to speak to a trained volunteer
0808 801 0322 hello@bliss.org.uk

Support on the neonatal unit

Bliss Champions offer emotional support and information on the neonatal unit. Ask if your unit has a Bliss Champion

Want to continue reading Little Bliss?

Sign up online at
bliss.org.uk/little-bliss

Search BlissCharity

