

Spring/Summer 2018

Little Bliss

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

So proud

Isla's mums talk IVF, premature birth and getting through neonatal care

Your rights

What to expect from your employer when your baby is in hospital

Parent tips

What to ask your neonatal team

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

Inside...

Your stories

5 A dad's time in NICU

Ben talks about how he coped when his daughter Nancy was born at 26 weeks, and how he helped other dads

10 Look at them now

We celebrate the milestones of babies in neonatal care with our new Bliss Baby Cards

12 Living with cerebral palsy

Kayleigh tells us what it's like to live with cerebral palsy as she celebrates the birth of her first child

16 "Isla makes us so proud"

Mums Kizzy and Sally talk about their experience of IVF and having a premature baby

Features

20 What you can expect from your employer

Find out what you're entitled to and how your employer can support you when your baby is in neonatal care

22 Things you could ask your neonatal team

Don't know what to ask the staff on your unit? Our parents have some suggestions

24 How can I care for my baby on the neonatal unit?

We've created a checklist to help you get involved in your baby's care and we share our top tips for nappy changing

26 Bliss helpline volunteer: five questions families ask me

Emma tells us what parents commonly ask when they call and email the helpline

Best of Bliss

29 Bliss updates

The latest on our upcoming mental health information, new Centre of Excellence and our training for health professionals

30 Why I help Bliss fund research

How Bliss' new research fund works, written by Ben who was part of a groundbreaking study as a premature baby

32 Leaving a gift to Bliss in your will

Stuart tells us why Bliss is important to his family and why his mum decided to leave a gift in her will to charity

34 In pictures: fantastic fundraising

We share some of our favourite fundraising photos and tell you how to get involved and help premature and sick babies

Little Bliss is reviewed by parents with direct experience of neonatal care. For information about their role visit bliss.org.uk/parent-panel

Little Bliss Issue no.40

Editor: Gemma Collins-Ellis **Design:** Joana Águas

🏠 2nd Floor Chapter House, 18-20 Crucifix Lane,
London SE1 3JW 📞 020 7378 5747 ✉ little@bliss.org.uk
🌐 bliss.org.uk/littlebliss

Bliss does not endorse any companies mentioned in this magazine and takes no responsibility for any action taken as a result of anyone reading this information. © Bliss 2018. No part of this publication may be reproduced without prior permission from Bliss. **Registered charity no. 1002973**
Scottish registered charity SC040878

Bliss information for parents

We have a range of information for parents who have a baby in neonatal care or are caring for a baby born premature or sick at home.



About neonatal care



Procedures and medical conditions



Being involved in your baby's care (family-centred care)

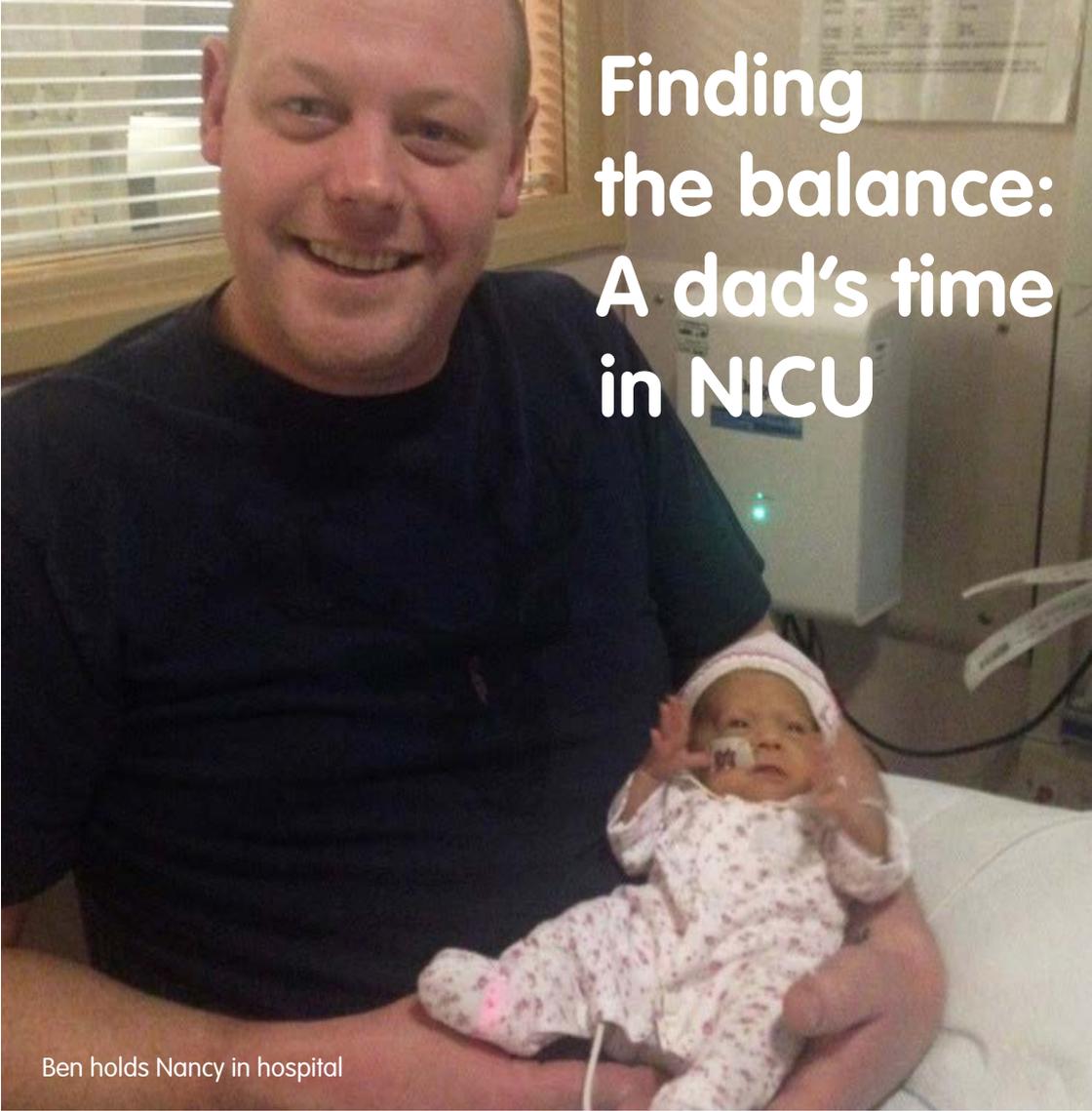


Weaning your premature baby

For online, video and audio information visit bliss.org.uk

For hard-copy information visit bliss.org.uk/shop

Finding the balance: A dad's time in NICU



Ben holds Nancy in hospital

After finding out his wife was pregnant with their second child, Ben didn't have much time to wait until he met his daughter, Nancy, who arrived at 26 weeks.

"Victoria and I were both anxious and excited when we found out we were having another baby. Victoria had

complications in her first pregnancy but our daughter, Yvie, was born at term and weighed over 10lb.

"At 25 weeks, Victoria was admitted to hospital and given steroid injections to strengthen Nancy's lungs. It was obvious that she was on her way."

Victoria gave birth to Nancy at Barnet General Hospital weighing only 755g.

“Being in the delivery room was the worst experience of my life. I thought that Nancy was stillborn because she wasn’t moving and was red and see-through. She was immediately placed in a plastic bag and taken away for treatment. We didn’t get the chance to hold her like most parents do.”

Once assessed, it was decided that Nancy should be transferred to University College London Hospital (UCLH) for specialist care. Ben followed behind in his car.

“I still remember how scared I was driving behind the ambulance at night through London knowing that Nancy was inside. She was so small and fragile when she was born and we were terrified about what was going to happen to her.

“When I went into the NICU for the first time, it was completely daunting.

It felt like a factory. There were so many noises, machines and people all doing different things. I didn’t want to ask questions about what the machines were for because I felt like I was getting in the way of the staff doing their jobs.”

“At last this baby I’d been looking at through the incubator felt like my daughter”

Victoria had an infection so couldn’t be discharged from Barnet for a few days. Ben spent that time taking photos and relaying medical information between the hospitals.

“We felt very apart from each other. Victoria felt especially separate – she still hadn’t seen Nancy and being away from her was heartbreaking.

“I remember taking the Tube between hospitals two or three times a day with syringes of breast milk for Nancy. The first few weeks in the NICU were



Nancy has skin-to-skin with her mum



Nancy spent 17 weeks in hospital



Nancy was the size of a teddy at birth



Enjoying kangaroo cuddles

very hard on the family. And for the first month, Nancy didn't respond to treatment. She was limp and grey and had to be massaged back to life by doctors on multiple occasions."

"Ask all the questions you need and hold your child as soon as you are able"

Before long, Ben had to go back to work and had to juggle things at home whilst taking care of three-year-old Yvie.

"When I went back to work I couldn't concentrate on anything. Some might consider the change in environment a welcome distraction but I was constantly thinking about our family.

"Even though the worry was always there, we got into a routine and the juggling that was required. Victoria would stay with Nancy in hospital all day and I'd go when I finished work. We'd often take Yvie with us but also

had a lot of support from Victoria's sister-in-law."

Once Nancy became more stable, she was transferred back to Barnet where Ben was able to hold her for the first time.

"At first, we hadn't been allowed to hold her and then I became scared of the idea. The nurses tried to encourage me but I felt too clumsy. I knew that I could probably fit her in one hand and was terrified of hurting her. Once I got over the fear, I finally started to bond with Nancy. At last this baby I'd been looking at through the incubator felt like my daughter."

The family had a private room due to Nancy being reverse-barrier nursed (a form of strict infection control that aims to protect patients against infection from medical staff) and were often left in charge of Nancy's cares.

This helped Ben and Victoria continue to bond with her. When other dads on the unit were having a difficult time, the nurses asked Ben to chat with them.

The family are still in touch with some of the parents today.

"I'd tell any dad on the neonatal unit to make sure that they don't leave everything up to mum and get involved from the outset, make sure you ask the staff all the questions you need – even when you are scared of the answer – and hold your child as soon as you are able."

In total, Nancy spent 17 weeks in neonatal care.

"When she was eventually discharged, she was on 13 types of medication. We were in and out of hospital with her for almost a year, which was emotionally exhausting; several blue light ambulance journeys made it all the more worrying.

"I always expect the worst but with the help and support from all the amazing staff we were able to get through it. They really became a part of the family and we are truly indebted to them.

"Nancy is now four years old and has been discharged as an outpatient. I'm looking forward to seeing what life has in store for our little fighter."

Ben decided to give something back to Bliss for their support whilst Nancy was in hospital. "My friends and I decided to travel 1,450 miles from Scotland to Cornwall on vintage motorbikes to raise money for Bliss. I raised over £16,000 from friends and family.

"I first became aware of Bliss' work when I was at UCLH on my own. The walls were covered in Bliss posters and the success stories of premature children who were now doing well gave me hope. I hope that the money raised will help the charity continue to support parents like me."

If you have been affected by any of the issues raised in this article, please call our helpline on 0808 801 0322 or email hello@bliss.org.uk

If you'd like to support Bliss' work for premature and sick babies visit bliss.org.uk/get-involved



Reaching milestones and making progress



Nancy (right) with older sister Yvie

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

always open at [mothercare.com](https://www.mothercare.com)

Look at them now

From the first cuddle to leaving the incubator, milestones in neonatal care are worth celebrating. We teamed up with parents to create Bliss Baby Cards, ten beautiful cards marking important steps in a baby's neonatal journey. We gave a pack to parents at the Royal London Hospital and they told us which milestone meant the most to them.



Zahra was born at 36 weeks in July last year, full-term but sick. Her mum, Neelab, chose the "Today I left the incubator" card because it was such an important milestone.



Noyan chose the card "Today I had milk without a tube" for his baby boy who was born at 35 weeks. In this picture he is two weeks old and has just progressed from tube feeding.



Ivy was born at 36 weeks with duodenal and oesophageal atresia, which means she needed surgery to connect her digestive system. Ivy had just reached her due date on the week we visited.



Harsimran was born at 38 weeks. She spent her first week in NICU and had just left the incubator and arrived in special care the night before our visit.



With many thanks to the staff on the neonatal unit at the Royal London Hospital.



Free Baby Cards for families in neonatal care

Get yours at bliss.org.uk/shop/baby-cards using the code **LittleBliss40**

Living with cerebral palsy



Kayleigh was born in 1989

Charity worker and new mum Kayleigh was born 10 weeks early almost 30 years ago. After being discharged from hospital she was diagnosed with cerebral palsy; here she tells us what it's like to live with the condition.

"I was born at 30 weeks weighing just over 3lbs. The first time my parents saw me was when a midwife gave them a Polaroid picture. My dad told me they were very worried and my mum didn't want to buy a pram in case I never came home."

But Kayleigh was strong and after five weeks in the neonatal unit she was discharged.

“Apart from being smaller than other babies (my nappies came up to my armpits) I progressed like anyone else. It wasn’t until I was 18 months old that people realised that something was not quite right. Even though I was using the furniture to get around on my feet, I was not letting go to attempt to walk on my own.”

Kayleigh was then diagnosed with cerebral palsy diplegia.

“No two people with cerebral palsy are the same. Much of my condition has affected my legs, meaning I am unable to walk. I also have weak hands so buttons, zips and shoelaces are an impossible task for me.

“I have spasms which are often triggered by my emotions or tiredness but I am able to control them to a certain extent and at the moment I do not take any medication.”

During her childhood, Kayleigh used a walker and had regular physiotherapy to strengthen her legs.

“When I reached 13 it was getting more difficult to use my walker. It was decided that I needed an electric wheelchair full time. Some people might have seen an electric wheelchair as giving up, but I didn’t. At the time I was in a lot of pain and using my manual wheelchair was too tiring. I have used my wheelchair ever since. I am proud of it and it’s a part of me.”

Kayleigh attended mainstream school throughout her education, leaving with eight GCSEs which opened the door to college.

“College is where I became truly independent. I studied travel and tourism and loved every single moment.

“Then there was an opportunity to do a foundation degree programme, so that’s what I did.



Kayleigh with her mum at hospital and at home



Kayleigh now works for Livability



Kayleigh enjoying motherhood

“I was given all the equipment I needed and for the first time I was independent with no classroom assistant. I then graduated at the highest level.

“After two years I moved on to university. I graduated with a 2:1 and decided to stay on and complete a master’s degree.”

“No one knows what your child can do better than them and you”

The day after her final exam, Kayleigh received a phone call from the charity Livability offering her a job. She happily accepted the role and has been working for them for six years.

“Not long after, I met my partner Jon. By Christmas 2015 I achieved my biggest step to independence when Jon and I bought our first house together.

“We have been joined in our adventure by our little girl. Eleanor was born in January 2018 and she is perfect.

“People often ask me what I would say to parents who discover their baby has a disability. I would tell them not to be afraid. Read up about the condition and find out what physical and financial support your child and you, as parents, are entitled to. Try not to get too caught up in the medical jargon or wrap your child up in cotton wool. Every child is different and no one knows what your child can do better than them and you.

“Most of all, there is no right or wrong way when it comes to disability. Often the child just needs to discover their own way. It is scary and sometimes difficult but we all find our way in life in the end.”

This is a shortened version of Kayleigh’s story – to read it in full visit bliss.org.uk/kayleighs-story

Heroes assemble!

Host a Bliss Little Heroes superhero walk this year



Get your free fundraising pack at bliss.org.uk/littleheroes



“Isla makes us so proud”

Kizzy and Sally desperately wanted a baby. After numerous fertility tests, mandatory counselling and an 18 month wait for a sperm donor they could finally start trying. But in spite of their struggle to get pregnant, the hardest part of their journey was yet to come.

When Kizzy and Sally received a letter from Liverpool Women's Hospital to say a donor had been found, they were over the moon. They immediately began trying to conceive the baby they had been waiting for.

“My partner Sally was going to carry our baby and we paid for six cycles

of IUI treatment (donor insemination) which were sadly unsuccessful. We then qualified for two rounds of IVF, but only needed one as Sally became pregnant after the first try.”

After a bumpy start Sally’s pregnancy continued without any trouble until 27 weeks.

“We were out shopping for new clothes for Sally as she was finally getting the bump we had been longing to see. She felt uncomfortable and eventually stopped for a drink. Suddenly Sally went pale and I could see the panic on her face. She said, ‘Kizzy something has just popped’. I called an ambulance and Sally was rushed to hospital.”

The doctors soon realised Sally was in labour and they began trying to stop it.

“They wanted to give Sally two courses of steroids to help the baby’s lungs. The first was given at 7pm and the second would be administered 12 hours later, but we needed to hold on.

“We were both so overjoyed but conflicted: how could we feel so excited at such a worrying time?”

“During this time the consultant came to see us and explained that if the baby was delivered they would be put in a plastic bag and monitored closely. Thankfully, 7am came and the second steroid was given. By the looks of things they had managed to stop Sally’s labour, what a relief! Later that night the hospital insisted I go home for some rest. Needless to say I didn’t sleep at all.”

The following day Kizzy got a call from the hospital to say Sally was in labour again.

“I rushed to the hospital and was taken straight to the room where Sally was. To my surprise Sally was sitting in a chair beside her bed looking well.



Isla on the day she was born



Kizzy and Sally with Isla, five days old



Sally giving Isla her first bottle



Going home at nine weeks and two days

I put my arm around her and asked, 'how are your pains.' She looked up at me and said, 'It's a girl'.

"I was suddenly overwhelmed with emotion. Anger for not being there when she was born, excitement to have a newborn baby girl and then worry and fear for my baby all rolled into one.

"Having her little body so close was overwhelming. It was amazing to feel her skin on mine"

"Our baby girl, Isla, was taken straight to the neonatal unit and later that day I got to meet her for the first time. Wow, she was the most amazing tiny baby I have ever seen. We were both so overjoyed but very conflicted: how could we feel so excited at such a worrying time?"

The neonatal staff helped Kizzy and Sally to care for Isla. "We were able to change Isla's nappy and wash her. It felt so special to contribute to her care as everything else was in the hands of the nurses and doctors. Most of the time we would sit looking at Isla wishing there was more we could do for her. We got to hold her at five days old and it was the most amazing moment.

"The nurse carefully placed Isla in each of our tops. Having her little body so close after looking in at her for so long was overwhelming. It was amazing to feel her skin on mine."

Unfortunately, just a week later Kizzy and Sally were told Isla may have meningitis and fluid on her brain. The couple were devastated, asking "why our baby?" Isla was given antibiotics and her brain was monitored in case she needed a shunt. She responded well and fought the infection. Kizzy says: "How such a tiny little body can be so resilient is amazing."

She continues: "Some days on the neonatal unit were okay and others were really difficult. We just kept hoping Isla would make it. Eventually she began to need less breathing support until she was nearly breathing on her own. Not so long after, she took her first bottle. She was then able to maintain her body heat and was moved out of her incubator into a cot.

"We got support from a Bliss volunteer who visited us every time she was in the unit. Her visits were something we looked forward to"

"She then graduated to the nursery and we knew that this was the last step before home! After two weeks and one day in the nursery she was allowed home on oxygen.

"Along our journey we met so many parents going through what we were going through and without these people we would have been lost. We all helped and supported each other through the highs and lows. We got support from a Bliss volunteer called Nicola who visited us every time she was in the unit. We got to know her and it really helped to have that support. Her visits were something we looked forward to.

"Isla was on oxygen for five months and came off just in time for Christmas - it was the best Christmas present ever. She is now 20 months old and is doing really well. She still sees the doctors at our local hospital for her chronic lung disease but she's a strong and determined little girl who doesn't fail to make us proud every single day."

If your baby is in neonatal care why not visit bliss.org.uk for information and support? We also have volunteers like Nicola in neonatal units across the UK. Ask your unit if they have a Bliss volunteer and when they visit.



Home on oxygen at seven months



Kizzy and Sally with Isla at 20 months

What you can expect from your employer

Many employers are understanding and flexible when a baby needs neonatal care, but not all are. To help you know what you're entitled to we've answered these common questions from parents.

My baby was born premature – when does my maternity leave start?

If you're not yet on maternity leave and your baby is born early, your leave will start the day after your baby is born. You'll need to let your employer know that your baby has arrived early and submit your MAT B1 form – which you should have received around your 20 week scan.

It is important to submit your MAT B1 form so you can start receiving statutory maternity pay or maternity allowance. Neonatal nurses are not able to sign the MAT B1 form, so in some circumstances you may need to go to your GP to get it signed.

My baby was born premature or sick – when can I take my paternity leave?

As a dad or partner, you are entitled to either one or two weeks' paternity leave. We know that this can be extremely hard and many people have to return to work while their

baby is still in neonatal care. You are entitled to take your paternity leave and pay within 56 days of the birth. This leave cannot be taken before the baby is born.

What if my employer isn't fulfilling their obligations?

ACAS Guidance outlines what employers can do to support parents. You can find *Workplace support for parents with premature or sick babies* at acas.org.uk/prematurebabies which may be helpful in reminding your employer of what they can do to help you. You can also call or email the Bliss helpline on **0808 801 0322** or hello@bliss.org.uk

“When my daughter was born my employer was supportive. Not everyone is so lucky. I think the ACAS guide is a good start but legislation needs to take it further to help parents at such a difficult time”

Sam Wallace,
parent to baby born at 28 weeks.



What happens if my baby dies, will I need to return to work immediately?

You are still entitled to your maternity, paternity or shared parental leave and you will not need to return to work straight away. Mothers who are eligible for maternity allowance can still claim this as well. You are also entitled to all of this if your baby is stillborn after 24 weeks of pregnancy or if your baby is born before 24 weeks but sadly dies.

A new law is going through parliament that would give parents two weeks of paid bereavement leave if their child dies, which would be separate to parental leave.

We hope that in the future this will help families who find themselves in this unimaginable situation.

If your baby has died or you are facing bereavement support is available for you from the charity Sands by calling **0808 164 3332** or emailing helpline@sands.org.uk

Could you lend your voice to help babies born premature or sick? Our campaigners raise awareness on issues such as parents' rights, support for families, funding for units and much more.

Join our campaigns network and help keep babies' voices at the heart of decision making: bliss.org.uk/campaign-with-us

Parent-to-parent: questions to ask your neonatal team

You should feel able to ask your neonatal team about your baby's care, but it's not always easy to know what to ask. Here, parents who have been through neonatal care give their suggestions.

Antony says: "Ask 'how can I get involved in my baby's care?' I think a lot of parents feel useless but there are ways to make a big difference whether that is doing cares, expressing milk or offering your opinion on behaviour trends you have noticed in your baby."

"Sometimes the best question is just 'What's the plan for today?'"

Stephanie

Georgina says: "Ask what all the alarms mean, that way when one goes off you know whether or not you need to call a nurse. Knowing this helped me feel more at ease."

22 | Your stories

Priya says: "Ask about what support is available to you as parents. It's often when you've left that you may start to feel not quite yourself and it would be useful to know who you can talk to or what resources might be available to help you. I fell apart six months later and through a local mum's intervention I got the help I needed."

"If something is worrying you or you don't understand something, just ask."

Kirsty

Parent-to-parent is a regular feature in *Little Bliss*. Read *Ten things you can do for your baby on the neonatal unit* and *Parent-to-parent: asking for help* at bliss.org.uk/your-stories



The only nappy designed for even the smallest babies

Pampers Premie Protection nappies come in three sizes for babies weighing between 1.8lb/0.8kg and 5lb/2.3kg.

Available nationwide. Ask your neonatal nurses today how to get yours.

In partnership with

Bliss
for babies born
premature or sick

The Pampers logo features a yellow heart with radiating lines above the brand name. The background consists of overlapping yellow and teal circular shapes.

Pampers
Premie
Protection™

You asked, we answered

'How can I care for my baby on the neonatal unit?'

You and your family can be involved in caring for your baby on the neonatal unit and you should be supported by healthcare professionals to do this.

This is called family-centred care.

It can help you to bond as a family, feel more confident as a parent, and it is linked to better long-term outcomes for babies' development.

Do you know some of the ways you can be involved in your baby's care? You might like to go through this check-list with a healthcare professional and see what they can help you to do.

Find out more about family-centred care and how it can help you and your baby by watching our video at bliss.org.uk/family-centred-care

Did you know?

Our Bliss Baby Charter shows what great family-centred care looks like and helps neonatal units to make changes that last. Find out more at bliss.org.uk/baby-charter

Family-centred care checklist

Tick the ones you've done

- Feeding your baby
- Washing your baby
- Dressing your baby
- Changing your baby's nappy
- Watching and learning from your baby
- Skin-to-skin with your baby
- Having all the information you need
- Asking about financial support you could get, like free parking or food vouchers
- Asking which family members can visit
- Creating a memory book
- Being involved in talks about your baby's care (for example, during ward rounds)
- Comforting your baby during difficult procedures
- Getting emotional support for you and your family

Tips for changing your baby's nappy

Changing your baby's nappy is a great way to be involved in their care on the neonatal unit. Here are some tips to help make it easier.

1

Before you begin, make sure you have everything you need to hand, so you won't need to break contact.

2

Approach your baby quietly, speaking softly.

3

Keep lighting, noise and activity levels low.

4

Take time and respond to your baby's signals. If they seem upset or unsettled then taking small pauses can help keep them calm.

5

Avoid lifting your baby by the legs. Instead, hold their feet sole to sole and gently flex their legs towards their body.

6

Stay close to your baby for up to 20 minutes after a nappy change to give continued support.

Have you heard that Pampers have created the smallest ever nappy for babies weighing less than 1.8lb? And they partnered with us to give the new Premie Protection nappies free to neonatal units across the UK. Ask the team on your unit for some for your baby.

Bliss helpline volunteer: five questions families ask me

Emma is one of the trained volunteers who supports families through our confidential helpline and email service. She responds to queries of all kinds from families across the UK. Here she tells us more about how the service works.

What is the Bliss helpline?

The Bliss helpline is an information and support service. Calls and emails are answered by volunteers, who are trained by Bliss to provide support to those who contact us. We support families, friends and anyone affected by neonatal care. People who contact the helpline are either experiencing neonatal care, or have experienced it in the past.

“Sometimes callers just want to talk and we’re here to listen”

What support does the Bliss helpline provide?

We listen and provide emotional support and information. We do this via telephone or email. Some common questions asked on the helpline are:

- Is there any support available to help me financially?

- What is happening on my unit? What do things mean?
- What happens when my baby goes home?
- How do I wean a premature baby onto solid foods?
- Can I defer my child starting school?

We signpost callers to our information and other support services, as well as to other organisations who might be able to help. Sometimes, callers just want to talk, and we’re here to listen.

Who can contact the helpline?

We support anyone who has been affected by a baby spending time in neonatal care. We aren’t there just to support mums – we are also here for partners, grandparents, other family members or friends. Having a baby in neonatal care can affect many family members and we’re here to support them all.



Emma won an award for Championing Babies' Voices at the Bliss Thank You Awards 2016.

I don't really have any questions – I just want to talk. Can I still contact the helpline service?

Of course you can! We're here to listen and offer support and information if you need it. Bliss helpline volunteers are trained to listen to callers. We understand that sometimes, you might just want to talk to someone and to know that you are not alone. We also know that some callers don't know what to say or ask, and that's okay too. Just give us a call. We are here for you.

When can I contact the helpline?

The helpline opening hours are:

- Monday to Friday, 10am to 12 noon, and Monday to Wednesday, 7pm to 9pm.

- If you need to call outside of these hours, there is an answerphone where you can leave a message. We'll call you back the next working day.
- You can also email us anytime and we will get back to you within three to five working days.

Call or email the helpline on ☎ **0808 801 0322** ✉ **hello@bliss.org.uk**

Pregnacare®

UK's
No.1
PREGNANCY
SUPPLEMENT
BRAND*



Proud to support
the **Bliss Helpline**

For more information visit
bliss.org.uk/helpline

With you every step of the way



BEFORE CONCEPTION

Carefully balanced formulation with folic acid recommended for all women trying to conceive.



ORIGINAL

19 vitamins and minerals, with folic acid and vit. D as recommended by the Department of Health.



LIQUID

Great tasting orange liquid for those who prefer not to swallow tablets.



BREAST-FEEDING

Includes 10mcg vitamin D and 300mg DHA for mums during lactation.‡



NEW MUM

With biotin and zinc to help maintain normal hair and skin.

BEFORE

DURING PREGNANCY

AFTER

From Superdrug, Holland & Barrett, supermarkets, chemists, health stores & www.pregnacare.com



The ONLY vitamin company to receive The Queen's Award For Innovation



VITABIOTICS
SCIENCE OF HEALTHY LIVING

*UK's No.1 pregnancy supplement brand. Nielsen GB ScanTrack Total Coverage Unit Sales 52 w/e 9 September 2017. ‡ A beneficial effect can be obtained from a maternal daily intake of 200mg DHA in addition to the recommended daily intake of 250mg DHA / EPA for adults - Annex of Commission Regulations (EU) No. 440/2011.

Bliss updates

Coming soon: mental health information and support

We will be creating some new information to help you take care of your mental health when your baby is on the neonatal unit. Like us on Facebook, Twitter and Instagram (@BlissCharity) and keep an eye on bliss.org.uk for updates.

Did you know Bliss trains healthcare professionals?

We support healthcare professionals to provide the best care for premature and sick babies, but not everyone knows about our training. The FINE (Family and Infant Neurodevelopmental Education) programme trains nurses, doctors, therapists and professionals from all areas of neonatal care.

The training covers brain development, parent and infant relationships and the parental journey, observing and understanding infant behaviour, managing stress and pain, feeding and kangaroo care or skin-to-skin.

One attendee said, "You do amazing work teaching us how to promote healthy babies. I'm proud to provide care which is evidence based."

Bliss has been pioneering the programme since 2014 and aims to train more than 300 healthcare professionals in the next two years.

Find out more about our work with professionals at bliss.org.uk/supporting-professionals

Bliss to create Centre of Excellence thanks to ICAP

Healthcare professionals caring for premature and sick babies will have access to educational resources in the new Bliss Centre of Excellence, funded by ICAP.

ICAP is a leading financial markets operator that gives away its profits to charity. Last year its charity day raised an amazing £8.2 million globally bringing the total amount raised over 24 years to nearly £135 million.

With the ICAP funding, Bliss will be able to design the Bliss Centre of Excellence, a new online membership portal for the neonatal community. It will be a place for professionals to collaborate and drive improvements in care for babies born premature or sick.

Why I help Bliss fund research

by Ben Wills-Eve

I was born extremely prematurely, at 23 weeks, back in 1990. I was fortunate enough to be enrolled on a research study which tested artificial surfactant, a detergent-like substance which helps the lungs inflate fully when breathing and stops them from collapsing – a major problem in very premature babies with underdeveloped lungs. All these years on, not only am I fit and healthy but surfactant replacement therapy has proven to be incredibly successful and a major factor in the increased survival rates of very premature babies.

My experience made me want to get involved with Bliss' new Research Grant Fund as a public panel member. I wanted to ensure that the researchers of today get the chance to make a similar difference for the babies of the future.

Bliss' Fund will award grants to researchers hoping to study three main areas: assessing pain in premature and sick babies, measuring the impact of developmental care and neurodevelopment and determining the most effective ways of giving emotional and practical

support to improve bonding between premature or sick babies and their families.

Any researcher who applies to the fund will go through two rounds of long and shortlisting. If the amount of money requested is more than £10,000 then their application will be reviewed by two independent experts and the panel that I sit on.

“We hope to fund research that tackles underlying medical challenges in a way that is practically useful and relevant to babies, parents and families”

The panel is made up of six professional members (healthcare professionals and academics) and seven public members (parents, family members and adults who were born prematurely) with public and professional co-chairs. Having equal representation from professional and public members was important when deciding on our research areas.

For example, we said more research is needed into pain, neurodevelopment and bonding, but practical support for these is equally important from a

parents' perspective. By focusing on these combined areas we hope to fund research that tackles the underlying medical challenges in a way that is practically useful and relevant to babies, parents and families and takes their experiences into account.

Despite the advances in neonatal care in the past 20 years alone, the breadth of these research areas shows how little is still understood in some types of care and therefore why research is so important. I am pleased and proud

to be on Bliss' Research Grant Panel and contribute to work that could make such a big difference to premature and sick babies.

Bliss is a charity and we're only able to fund research thanks to the support of our generous donors and fundraisers. To help us support more research please make a donation at bliss.org.uk/research-appeal

Funding research that is practically useful and relevant to families





Why my mum left a gift to Bliss in her will

by Stuart Amos

I first heard about Bliss when my wife Aimee was admitted to hospital. She was 24 weeks pregnant with our first child. We never imagined that our baby boy would be born so early – we weren't prepared for it. George fought hard, but sadly he died shortly after birth. We were both devastated. How could this happen to us?

While we were in hospital, we read some Bliss publications. We dismissed them at first because you hope

you won't need them. After George passed away, we re-read them and came to appreciate the support that Bliss offers families like mine who've gone through the heart-wrenching experience of having a premature baby. That Christmas we asked our friends and family to donate to Bliss instead of giving us presents. It was the least we could do to help ensure that other families and their babies get the help they deserve when they need it most.



Aimee, Stuart and son Bertie



Bertie now

“When Bertie was born early we were better prepared because we knew we could turn to Bliss”

Aimee and I were thrilled to find out she was pregnant again the following year with our second child, but sadly Harry was stillborn. We were devastated all over again. It was an incredibly difficult time for our whole family.

For my mum, Joan, George and Harry's deaths rekindled memories of my brother David, who was born prematurely in 1977 as a result of complications in pregnancy caused by a car crash. David was born with a number of disabilities and passed away at the age of three in 1980.

Before she died, mum decided that she wanted to acknowledge David, George and Harry properly in her will,

and as she knew that Aimee and I had benefitted from Bliss' support, she decided to leave a gift to Bliss from her estate.

When our third child, Bertie, was born four weeks early, we were better prepared because we knew we could turn to Bliss for information and support. Incredibly, Bertie only spent three days in hospital, but during that time we found all the information and support we needed on the Bliss and Netmums forum.

Bertie's doing so well now – we can hardly believe the progress he's making! Bliss has played a big part in helping us on our journey and it's gratifying to know that my mum's gift will help ensure that even more vulnerable babies have the best possible start in life.

To find out how to include a gift to Bliss in your will, please visit bliss.org.uk/giftinyourwill

Alternatively, please call Rachel Hedley on 020 7378 5740 or email rachelh@bliss.org.uk

Do something amazing

We have some incredible fundraisers. People who never fail to amaze us with their passion, creativity and fearlessness. Here are just a few examples of people who've raised money for us, and how you could join them in supporting premature and sick babies this year.



Bliss Little Heroes – a sponsored superhero walk March to October

"We did it! We made it to the summit for sunrise which was incredible! It took all of our strength to keep going to the top! We are so pleased to have made it" **Amy and Lydia**

"It was a beautiful day that I feel has been part of our healing process. Thank you for giving us the opportunity to not only fundraise but to have a little light therapy by doing so." **Katy**



An overseas adventure - Mount Kilimanjaro Trek
2018: 24 Aug-02 Sept
21 Sept-30 Sept
2019: 22 Feb-03 March



Golf club activities All year round

"As a club our target was to raise £2,500 over the year, but we smashed it in one day! I am so pleased that we could raise that much for Bliss!" **Phil**



Something out of the ordinary –
host your own event

“It was a great experience and I was very very lucky the bees were calm and I didn’t get stung!” **Ben**

“Cadi’s neonatal journey touched so many people in my community who were so generous with their donations. They flooded in! My twin sister also signed up to cycle 100 miles and helped raise £500.” **Jocelyn**



Go the Distance for Bliss – a 27 or 100 mile virtual event **September**



Run for Bliss All year around

“Another run complete and it was even more special as we got to take all these beautiful babies along for the adventure too. A perfect way to raise more awareness of neonatal care and infant loss.” **Megan**

What could you do? Visit bliss.org.uk/events to see all our events and to find yours



Bliss is here for you

Information and support

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

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

Want to continue reading Little Bliss?

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

Peer support

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

Support on the neonatal unit

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

Search BlissCharity



Registered with
**FUNDRAISING
REGULATOR**

Bliss
for babies born
premature or sick