Mental wellbeing support on the neonatal intensive care unit (NICU)

If your baby is unwell or has been born prematurely, they may need to stay in the neonatal intensive care unit (NICU) for treatment. Understandably, this can be a very distressing and exhausting time. Parents of babies who have a stay in the NICU are at greater risk of anxiety, depression and post-traumatic stress disorder (PTSD) for months, or sometimes years, to come.

This factsheet provides information about the support we can offer parents to help them look after their emotional and mental health. If you have any further questions or concerns, please speak to a member of your healthcare team who will be pleased to help you.

Emotional support

Many parents often describe being on the NICU as an 'emotional rollercoaster'. Your emotions may feel overwhelming, foreign or confusing at times, but these are all natural responses to a difficult situation.

Every parent copes differently, but you may feel:

- helpless in the face of so many uncertainties
- overwhelmed
- shocked and numb
- guilty or in some way responsible for having a premature or unwell baby
- like you're not a 'proper' parent
- stressed, tearful or low
- angry
- distant and find it difficult to 'think straight' or remember things
- detached and want to avoid being with your baby
- worried and find it difficult to leave your baby
- 'on edge' and panicky
- joy at meeting your baby
- pride in seeing them develop
- relief that your baby is receiving appropriate medical care

We will offer you emotional support throughout your time in the neonatal unit. Many parents find it helpful to talk about their feelings. Our neonatal counsellor and psychologist both have specialist training in helping families who have a sick or premature baby. We are here to listen, to think with you about what's happening, and to help you find a way through your time on the unit.

Leaving hospital with your baby

Leaving the neonatal unit for the first time with your baby can be one of the most challenging times for you as parents. You may experience several emotions, including:

- · feeling a huge sense of responsibility
- feeling scared to leave the support of nurses and doctors
- feeling overwhelmed
- · feeling isolated from friends and family
- having flashbacks of conversations and challenging days in the NICU
- feeling guilty
- · fearing for the future

It is important to understand that the experience of your baby's stay in the NICU may continue to affect your mental and emotional wellbeing in the years ahead.

Additional challenges

Parents often find that there are additional challenges that come from having a baby on the NICU. Challenges include:

- coping with feelings of uncertainty when your baby is transferred to another area or unit
- · maintaining a helpful and supportive relationship with your partner
- communicating about what's happening with family and friends
- · adapting to changes in your roles and expectations
- having open and helpful communication with medical and nursing staff
- organising family life outside the hospital
- supporting other children in your family
- · facing financial stress and uncertainty

How can speaking to a neonatal counsellor or psychologist help?

Speaking to a neonatal counsellor or psychologist may be a new experience for you, but parents often find that they need some help adjusting to what can be a very unexpected and stressful time on the NICU. Spending time with a neonatal counsellor or psychologist can help you to:

- express and explore your emotions in a supportive environment
- understand your emotional reactions and explore ways to cope with them
- help you manage the effects of your experience on your family relationships and relationships with your baby's medical team
- · find ways to solve problems and make use of your strengths and skills
- help you think through decisions you need to make about your baby's treatment

Talking about how you are feeling will help you get through the exciting yet challenging time of becoming a parent. It doesn't matter who you talk to, but it is worth having someone in mind that you can trust and who can support you if needed.

Our neonatal counsellor and psychologist both have special training to help people make sense of how they feel, think and act, and aim to reduce distress and help people cope by using talking therapies.

How to book an appointment for support

Speak to the nurse or doctor caring for your baby and tell them you would like to see a neonatal counsellor or psychologist, either on your own or as a couple. They will be able to organise an appointment for you. Usually you can be seen on the ward in a private room near to your baby. If you would like a break from the unit, there are also rooms at other locations in the hospital.

There may be a short wait for appointments. We will always let you know when you are likely to be seen.

Confidentiality

We may write to your GP to let them know you have been seen by us so they can continue to provide care for you once your baby has left the hospital or moved to a different setting. Information that you share with a counsellor or psychologist will be kept confidential.

Parents sometimes find it helpful to share some information with the medical team to improve communication and care. If there is a risk of harm to yourself or to others, then this information may need to be shared with other professionals. If this occurs, the psychologist will discuss this with you whenever possible.

Finding other sources of support

There are a number of other sources of support which may help you during your baby's NICU stay. Here are some different options to try:

Attend a support group

When you first arrive in the neonatal unit, we will welcome you and explain the resources that are available to you. Please ask us when the unit runs support groups, as these are a great way for you to meet other parents who are in a similar position. Bliss, the premature baby charity, also runs support groups across the UK.

Look out for 'parentcraft sessions'

Parentcraft sessions aim to involve parents in the care of their own child. Sessions include:

- what to expect when your baby is here
- how to help comfort your baby
- medicines
- meet the pharmacist

Join the 'Holding Little Hands' Facebook group

Holding Little Hands is a Facebook support group for parents where you can share your experiences and make new friends. You may then decide to form your own friendship group. Parents who make friends with other mums and dads in the neonatal unit often find that their shared experience makes them friends for life.

Read up on premature birth

Neonatal care is complex and the terminology can be overwhelming. The medical team caring for your child will do their best to explain, but it may help to read up on the subject of premature birth. For some people, this helps them to feel empowered and more able to make difficult decisions affecting their baby's care. We recommend reading 'The Preemie Parents' Companion' by Susan L. Madden.

Mindfulness

The Mind charity have published a series of relaxation tips and exercises that you can do regularly, or whenever feels right. To find out more, please visit www.mind.org.uk/information-support/tips-for-everyday-living/relaxation/relaxation-exercises

They also recommend spending time in green places, such as your local park, where you can tune out from your worries and experience mindfulness. Music therapy may also help.

Practice kangaroo care

Kangaroo care is the process of holding your baby to your skin. It has been shown to have many benefits including stress reduction and bonding.

Make time for yourself

It's common for parents to experience tunnel vision in the neonatal unit. We know that you want to be at your baby's cotside as much as possible, but for your mental and emotional wellbeing, you must make time for yourself. Head home or to the hospital accommodation and relax in a warm bath, have a walk or take a nap.

Supporting your mental health, so you can support your baby

Any parent can feel like their own needs take a back seat when their baby is born. We know that having a baby born premature or sick can increase parents' risk of struggling with their mental health. Everyone will face challenges differently, but whatever you're feeling, you are not alone.

Making time for yourself can make a difference. Other parents have found it helpful to:



Have a cup of tea or coffee



Get fresh air and natural light



Have a long shower, or bath





Read, watch TV, or listen to music if you enjoy these things



Do exercise that you enjoy, like going for a short jog, or taking a class



Spend time with your other children, if you have them



Spend time with your partner, friends or family



For information, tips, and stories from other parents about supporting your mental health on the neonatal unit, visit bliss.org.uk/mental-health





Share how you feel

We all process trauma in different ways. However, ignoring your emotions and not talking about your feelings can lead to extreme stress. Some parents find it helpful to write an emotional wish-list to communicate their thoughts and feelings to friends and family.

Contact us

If you need urgent help, speak to the NICU nursing team who will be able to arrange psychological support. If your mental wellbeing gets worse, please visit **www.mentalhealth.org.uk** and call one of the helplines available, such as the Samaritans.

If you are concerned that you are developing a mental health problem, you should seek the advice and support of your GP. If you are in distress and need immediate help, and are unable to see a GP, you should visit your local emergency department.

Neonatal intensive care unit (NICU)

Telephone: 023 8120 6001

Neonatal secretaries

Telephone: **023 8120 4643** or **023 8120 6007**

Email: neonataladmin@uhs.nhs.uk

Useful links

www.bliss.org.uk

www.nhs.uk/conditions/pregnancy-and-baby/baby-special-intensive-care

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone **023 8120 4688** for help.