

Managing your wellbeing on the Neonatal Intensive Care Unit (NICU)

Acknowledgements

The East of England Neonatal ODN and the East of England Neonatal Parent Advisory Group would like to thank the Psychological Medicine Service for Children, Young People and Families at Cambridge University Hospitals for allowing us the use of their document.



**Cambridge
University Hospitals**
NHS Foundation Trust

Managing your wellbeing on the Neonatal Intensive Care Unit (NICU)

For NICU Parents

We understand that having a baby on NICU is a really challenging time. Some parents describe it as an 'emotional roller-coaster'. You are also now facing additional challenges related to COVID-19. We have put together some guidance and resources to help you to look after your wellbeing.

Emotional wellbeing whilst on NICU

You might be experiencing a range of emotions whilst on NICU – from joy and excitement to sadness, anxiety or anger. All these emotions are completely normal. Below, we have listed some common experiences that parents have found difficult whilst on NICU. However, it is important to remember that everyone's situation is different and, whilst the experiences listed below are common, it might be that you are not experiencing any of these and that is okay too.

Anxiety: Parents can experience high levels of anxiety for their baby whilst on NICU and find that they spend a lot of time worrying. Being on NICU can also trigger obsessive-compulsive symptoms. This is completely understandable, given that the NICU environment involves many routines around hygiene and parents can feel an increased sense of responsibility for protecting their baby.

Low mood: You might find that you feel upset and experience periods of low mood. Spending time on NICU and caring for an unwell baby can feel physically and emotionally exhausting. Therefore, feeling low in mood sometimes is normal in the situation.

Feeling institutionalised: Being separate from your baby can feel unnatural. The NICU environment is very different from the home environment and it can be hard to adjust to getting to know your baby in this setting.

Guilt: Parents on NICU often feel guilty and might be convinced that they are not 'good enough' parents. For example, for some this guilt may exist around expressing milk and feeding their baby; for others it might be around feeling they did something 'wrong' in pregnancy. It is important to remember that many parents feel this way and it does not mean that you have done anything wrong.

Trauma: Some parents may find that they experience nightmares or feel that they are experiencing flashbacks of particular situations on NICU or the birth. This is a common experience for parents with a baby on NICU. These reactions are a normal response when facing highly threatening situations and are our brain's way of processing the trauma.

In light of the experiences above, it might be helpful to try some of the strategies in this booklet. If some of the symptoms above persist, or interfere with your day-to-day activities, please speak with a member of the family support team.

Ways to manage worry

Worry or anxiety is our body's way of letting us know when we are, or think we are, under threat. It is a helpful strategy for alerting us to danger and keeping us safe. Sometimes worry persists and it can make it difficult for us to do the things we want to do in our daily lives. At times when you are feeling anxious you might notice that your heart is racing; you might feel sweaty, shaky or short of breath. This feeling of unease can also cause changes in our behaviour, such as seeking more reassurance than normal or avoiding activities. It is important to remember that it is normal to feel worried during your baby's time on NICU and there is support available. There are lots of different ways to manage anxiety and different things will work for different people.

Information gathering

- With regard to COVID-19, it can be a good idea to limit when and how much news you listen to / watch / read and limit your social media usage, especially if this makes you feel more anxious. Try checking reliable sources just once a day.
- At times you might feel that the information you are receiving from the medical team is becoming overwhelming or difficult to absorb. You can let the NICU team know if you would rather not be updated one day unless there is something urgent you need to know.
- It can be helpful to write down key information from the medical team if you are finding it hard to process and remember it.

Worry-time

- If worries are there all the time, you can try having an allocated 'worry time' – a specific time each day when you can think through your worries. This can help to limit the amount of time and energy spent on worrying throughout the day. When a worry comes to mind outside of the 'worry time', acknowledge it or write it down, ready to think about at the allocated time.

Managing uncertainties

- When your baby is on NICU, things can often feel very uncertain and unpredictable.
- If you have questions, don't hesitate to ask the medical or nursing team as they are there to support you as well as your baby.
- There might be 'what if' questions you have that cannot be answered. If this is the case it can be helpful to:
 1. acknowledge the uncertainty.
 2. remind yourself that this is a thought, not a fact, and cannot be answered right now.
 3. step back from the thought and allow it to pass. For example, you might imagine it as a cloud moving in the sky.
 4. focus on the present moment by taking in everything around you. What can you hear, feel, smell, touch, taste? How does your body feel? Can you feel your breathing?

Talking about your worry

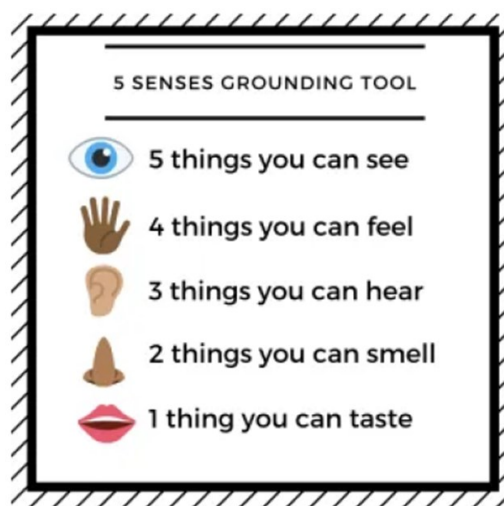
- It can be helpful to talk the worry through with someone; this might be with family, friends or staff on NICU.
- Some people find it helpful to write down their worries. You might find that this helps to clear some space for you to think about and do other activities.
- Ask a member of staff on your unit about what emotional and mental health support is available to you during your baby's stay on NICU where you can talk about your worries.

Relaxation techniques

- There are many different techniques you can use to help with physical sensations related to anxiety. Try the following ideas and practise what works for you.

Grounding yourself

- If you feel very overwhelmed, or start to feel disconnected from the present moment, try the following exercise to help you re-focus:



Controlled breathing

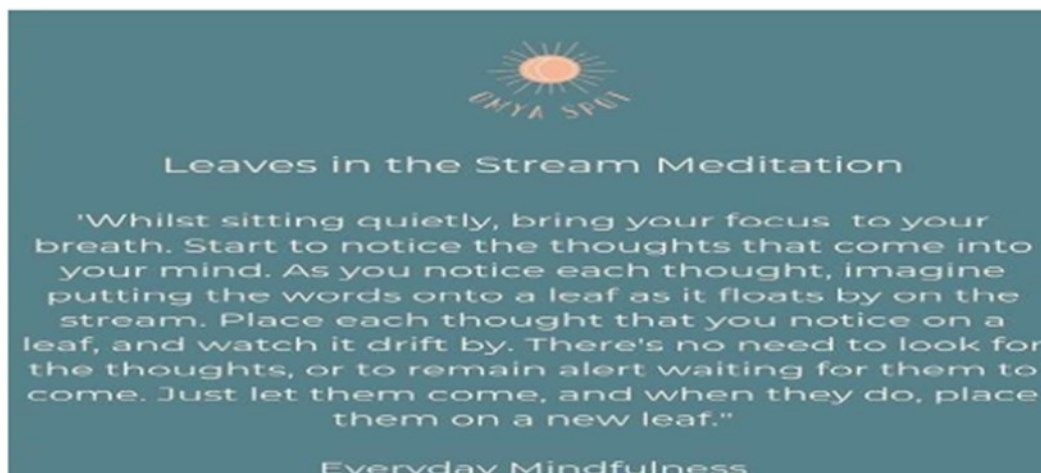
- Controlled breathing is a helpful way to combat the physiological symptoms of anxiety and help us to feel calm and can be practiced anywhere and at any time.
- Try breathing in through your nose for four counts and out through your mouth for five counts, as if blowing through a straw.
- The Breathe app (https://play.google.com/store/apps/details?id=uk.co.jatra.inout&hl=en_GB) is free to download from the App Store and provides a helpful support to learning controlled breathing. For Android devices, the breathe2relax app (<https://breathe2relax.soft112.com/download.html>) is a helpful breathing tool.

Safe place imagery

- Safe place imagery is a visualisation exercise that involves thinking of a calm, peaceful place. (It can be real or imaginary.)
- Whilst imagining this place, use all your senses to get in touch with what you can see, hear, feel, touch and taste in this peaceful place.
- It might feel easier to do this closing your eyes, in a quiet comfortable location.
- You can use the following website for more information on using this technique: <https://www.getselfhelp.co.uk/docs/SafePlace.pdf>

Mindfulness

- Mindfulness is the practice of connecting with the present moment in a non-judgemental way.
- Mindfulness exercises are a great way of managing with anxiety and uncertainty. They can help combat the physiological sensations of anxiety and focus the mind away from worries about the past or future, and focus on the “here and now”.
- Apps such as *Headspace* (<https://www.headspace.com/>) and *Calm* (<https://www.calm.com/>) are useful to help support you with mindfulness practices.
- The mindfulness exercise below can be helpful if you are having lots of anxiety-provoking thoughts:



Self-care

Planning in activities

It is really important that you take time to look after yourself and try to engage in self-care activities whilst your baby is on NICU. You can try to plan these activities around seeing your baby on NICU. Some people find it is helpful to make a list or a timetable for each day.

Here are some ideas of self-care activities...

- Sewing
- Jogging
- Watching a film
- Going for a walk
- Calling a friend or family member
- Taking a bath
- Going for a coffee / something to eat
- Reading
- Doing crosswords / puzzles

Creating a good sleep routine

Some parents find it difficult to sleep whilst their baby is on NICU. Here are some tips if you are having sleep difficulties:

- Do not drink caffeinated drinks after midday.
- Do not go to bed hungry and do not eat a meal within an hour of trying to sleep.
- Avoid screen time (mobile phones, computers, iPads/tablets and TV) for at least 1 hour before bedtime.
- Try listening to calming music, guided meditations, audio books or sleep sounds (there are apps that can help with this, such as Calm; <https://www.calm.com/>)
- If worries keep entering your mind, try keeping a notepad next to your bed and writing any concerns down that you can then review the next day.
- Try not to 'clock-watch' as this can increase frustration when trying to go to sleep.
- If you can't sleep, get out of bed and move elsewhere to do a relaxing activity (e.g. have a warm drink, listen to music, read a magazine) then try going back to bed when you feel tired.

Creating a self-soothing 'toolbox'

- Identify different activities and sensory objects that you find calming and enjoyable and have these easily accessible in your own 'toolbox'.
- Activities might include things such as colouring, knitting or drawing.
- Sensory objects might include things such as stress balls, different textured items (e.g. ribbons, soft toys), scented candles or bubble bath, photographs of important and positive people in your life or of a special place you have visited.

Caring for your baby on NICU

We understand that it can feel difficult for parents to feel involved in caring for their baby whilst on NICU. It is important to remember that as parents there are many activities you are doing (which you might not be aware of) that are having a positive impact on your baby, such as talking to them and engaging in positive touch. If you want to find out more about the things that you can do at the cot-side to help care for and interact with your baby, please speak to the nurse looking after your baby.

Keep in touch with the medical team looking after your baby

- If you are unclear about any of the information you have been given from the medical team, please do not hesitate to discuss this with NICU staff. A meeting can be arranged with the

Documenting your journey

- Some families have found it helpful to keep a diary whilst on NICU to mark milestones and note their feelings at the time.
- Some families like to take photos with milestone cards such as these ones from [Little Mouse](#) or these free ones from [Bliss](#)

Finding ways to stay connected with your baby

We are aware that the current visiting restrictions resulting from COVID-19 might make it harder for you to feel connected with your baby. We have included some suggestions below to help you to feel close to your baby in the current context:

- Ask staff for a Facetime session with your baby; this can be arranged at a suitable time.
- Take pictures and videos of your baby to look at when you are home.
- Use bonding squares to swap between you and your baby – please speak to a member of staff about this.
- Put up a photo of you / your family in your baby's cot.
- Talk about your baby with friends and relatives.
- Make a list of your baby's likes and dislikes to leave with the staff caring for your baby.
- Write a letter to your baby when you are not with them. You could then read this to them when you next visit.
- Read to your baby. This can be a storybook or even a newspaper, the sound of your voice is what is important to them.
- Set time aside to stop everything else and only think about your baby when you are at home. Some people might mark this time by doing something special, like lighting a candle.
- Speak to the neonatal team about how you would like to be updated about your baby.
- Ask the team about how you can get involved in your baby's caring routines when you visit them.

Here are some helpful tips for how other family members who can't visit can stay connected:

- If you have other children in your family, you can ask them to draw a picture, or write a story for your baby.
- You can record the voices of other family members to play to your baby when you visit them.
- Encourage those who can't visit to choose songs to play to your child, or toys to put in their cot.
- Show photos and videos of your baby to friends and relatives.

We are aware that you may worry about your attachment and bonding with your baby in the current climate. It is important to remember that bonding is a process; it's resilient, it's flexible and it keeps on developing throughout childhood.



Sources of support

- The team on your unit will be able to explain what emotional and mental health support is available to you during your baby's stay on NICU
- The chaplaincy service offers support to all parents. This support can include religious and spiritual support. They can also offer a listening space to parents who aren't religious. Please ask a member of the team if you would like a visit from a member of the chaplaincy team
- For more urgent mental health support please dial 111 or call your out of hours GP service
- Arrange a video call with a Bliss volunteer who is trained to understand neonatal care and experienced in supporting families. The call is an opportunity for you to ask questions, share your experience or just talk to someone who understands some of what you might be going through <https://www.bliss.org.uk/parents/support/emotional-support/remote-volunteer-support>

Supporting resources: Websites and online resources

Non-COVID resources:

1. Relax melodies: <https://www.relaxmelodies.com/home/?> for relaxation techniques for a better night's sleep.
2. APPLE: <https://www.getselfhelp.co.uk/apple2.htm> - for tolerating uncertainty.
3. Leaves in the stream:
<https://www.mindfulnessmuse.com/wp-content/uploads/2011/09/Cognitive-Defusion-Exercise-1.pdf> - a method of finding acceptance in a challenging situation.

COVID resources:

1. FACE COVID video: <https://www.youtube.com/watch?v=BmvNCdpHUYM> - education around normalising your fearful or anxious response to COVID-19.
2. Mind: <https://www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/> - finding ways to cope if you are worried or anxious about COVID-19.
3. Tips for managing mental health: <https://www.mentalhealth.org.uk/coronavirus> - how to look after your mental health during COVID-19.
4. Psychology tools: https://www.psychologytools.com/assets/covid-19/guide_to_living_with_worry_and_anxiety_amidst_global_uncertainty_en-gb.pdf - coping tools for living through anxiety and uncertainty during COVID-19.
5. Relate - advice and tips for healthy relationships:
<https://www.relate.org.uk/covid-19-our-advice-and-tips-healthy-relationships#.XnsqrVj3EVg.email> - tools to steady relationships during COVID-19.