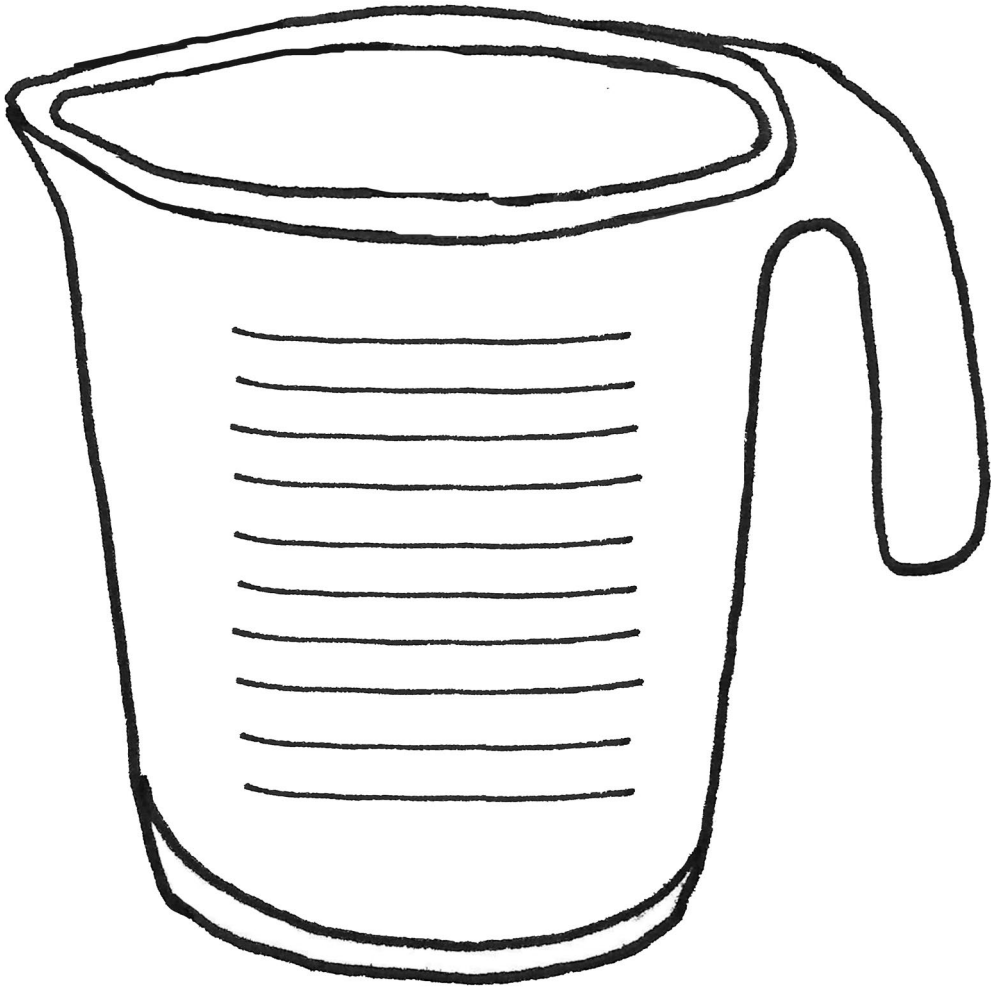
## ✓ ‘WHAT AM I HOLDING?’ IMAGINING YOURSELF AS A CONTAINER

Here is a container for you to complete for yourself. Think about what you have in your container and how much space it takes up for you emotionally. What you put in your container may be events and situations that are happening now or that may have happened very recently, but they can also be things from the past that have a longer-term impact.



*What I am holding* (*the contents of my container*)

## ✓ REDUCING WHAT YOU'RE HOLDING IN YOUR CONTAINER

Have a look at what's in your container and list anything that you acknowledge is there but that can be put to one side for now:

Make a list of what's in your container that needs *immediate* attention. This may be practical worries, concerns about care or emotional distress:

## ✓ ‘WHAT I NEED’

Think about what you need right now to help you in these first few days (bearing in mind that these needs will evolve and change during your time on the unit) to help with everything you’ve identified. This exercise breaks these down into different areas. You may wish to do this for yourself and then think about what you might need as a couple or as a family. Keep this list nearby and add to it as things come to you throughout the day.

‘What I need physically’, *for example, pain relief, help with moving, help with finding a comfortable sitting position to see my baby, sleep and rest, food/drink, help with expressing and breast soreness.*

‘What I need practically’, *for example, someone to look after my dogs, someone to inform work and friends of the situation, tops I can wear to hold my baby skin to skin, maternity and breast pads, mobile phone charger/credit, help with expressing equipment and timings and a map of nearby amenities.*

‘What I need emotionally’, *for example, time with my baby without too many visitors, open conversations with my partner and family and people around me on the unit who help me feel calm, confident and safe.*

'What I need from my partner' (you can discuss this together and think about how you can meet each other's needs), *for example, lots of holding and hugs, reassurance, encouragement and support when talking to the consultants*.

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'What I need in relation to my baby', *for example, time to be with my baby without other demands, cuddles or close touch when I can, time to talk and sing to them, time when I know they are more stable so I can wholly relax when I'm with them and minimal separation*.

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## MAPPING OUT A SUPPORT NETWORK

In the centre of the page is you. In each box are some types or areas of support to help get you started, and a space to write the names of people in your network who can provide this for you as well as a box to add others who are also important to you.

People who can provide a range of practical support, *for example, ensuring bills are paid, collecting and washing clothing, organizing childcare, cooking or delivering food, liaising with my employers, driving me to and from the hospital and feeding pets.*

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People who can help me with information gathering, *for example, finding out about maternity and paternity pay/rights, researching support groups for parents whose children have a similar issue and working out financial benefits or assistance.*

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People who can share information and manage my network, *for example, being the spokesperson on the phone and through social media, giving weekly updates and updating more distant relatives or acquaintances.*

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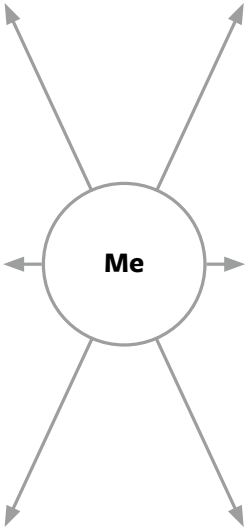


People who can provide support relating to my baby's condition, *for example, explaining what's happening in a way I can understand, talking me through what equipment or treatment they need and explaining plans and the reason for a particular approach.*

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People who can provide emotional support, *for example, listening to what is happening without judgement, validating my experiences, encouraging me, sitting with me and keeping me company, being in the hospital even if they can't come to the unit if I need them and helping me find ways to cope.*

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Other key areas and people who can support me in each of these:

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## ✓ ENHANCED COPING STATEMENTS/CARDS

If you are struggling to hold hope or find a way through the next moment, it may be hard to hold onto anything positive or comforting. Sometimes we don't even remember information that may offer a different perspective.

Making coping statements/cards either physically or on your phone is a way to remind yourself of important facts or encouragement of others when you can't recall them on your own.

Step one: Ideally with a partner or friend, make a list of anything that has been said to you about your baby or situation that has been helpful. Also include anything anyone has said to you about yourself that has been encouraging or made you feel better, even for a moment.

Step two: Imagine the tone of voice you need these statements to be spoken to you in right at this moment. You might want to use the voice of someone real in your life, or the voice of an imagined perfectly soothing and wise person.

Step three: If you find it is more effective to listen to recordings of these statements and you have a person who can do this for you, you could store them as a recording or video on your phone.

## MAPPING OUT A ROUTINE

Start to map out a routine based on a list of what is most important for you and your baby. List the most important things here:

1. .....
2. .....
3. .....
4. .....
5. .....

## NOTICING AND NAMING EMOTIONS

Think of some words to describe how you are feeling at the moment, *for example, I feel really overwhelmed. I'm terrified all the time, angry at everyone around me trying to help, powerless to do anything, guilty that I can't be there for my partner or my other children, so tired, so empty. At the same time I'm excited to see my baby and so pleased I can be here for her*.

My words/experience:

.....

.....

.....

.....

Think about experiences in your body that are linked to your feelings, *for example, I feel sick, I feel exhausted so much my chest hurts, my pain post birth recovery gets worse when I'm feeling all this, I sometimes can't breathe, my heart races and then I feel unwell – a bit like things are surreal or far away*.

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My experiences in my body:

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## WHAT'S IMPORTANT IN UNDERSTANDING YOUR OWN LIFE EXPERIENCES?

As you read these stories, think about the similarities and differences in your own life experiences that are important in understanding where you are emotionally. Make a note of those that come to the forefront of your mind, and notice how they may have shaped you over time, including how they have shaped your thinking about yourself and others:

## MAKE YOUR OWN CALMING KIT

Having a physical collection of objects with you that help you to connect to feelings of calm and connection with others can be very helpful. Think about your five senses and what object provides something either directly or indirectly that works best to increase your sense of comfort, familiarity and calm. Put these objects into a kit for yourself that contains everything you need and can easily travel with you. Jot down some ideas under each sense below, and then see the example of Taz's calming kit that he took to NICU and also to the parent accommodation so he could use it at night when he felt particularly vulnerable.

**Sight:**

**Touch:**

**Sound:**

**Smell:**

**Taste:**

## BEGINNING TO NOTICE PATTERNS

Notice when you are moving into a more anxious mindset, and what changes for you first. This may be physical sensations, thoughts or emotions, or a change in how you start to view what is happening around you. The better you become at spotting these changes, the easier you can put things into place to help prevent distress escalating.

Notice perhaps when you are in a calmer place any loops or cycles that you get stuck in when you feel anxious. It can also be helpful to identify the triggers for entering a loop, such as a particular event, conversation or feeling.

Here are some examples of the loops or cycles that can emerge:

> Thinking 'I am powerless to do anything in this situation' > feeling fearful > feeling more powerless and out of control as your threat system becomes progressively more activated.

Add some of the loops or cycles you might find yourself in here:

Identify particularly vulnerable times for anxiety in the course of your day, and problem solve how to manage these yourself and with others. Here are some examples:

| **Time/event that is likely to increase anxiety** | **What helps** |
|---|---|
| *Periods when my baby's oxygen levels are dropping (often referred to as 'desatting') and regularly setting off the alarms – feeling terrified of what's going on, what I should do and how someone is going to help – should I help?* | • *The nurse to clearly and calmly tell me what is happening and what she is going to do to help, step by step, also letting me know when I can assist and when I need to step back.*<br>• *To recognize that this is likely to set off thoughts and images that are distressing of something terrible happening to my baby, but that these thoughts don't mean this will happen or make something bad more likely.* |

| | |
|---|---|
| | • *To remind myself that whilst this is scary, it's common, and the team know what to do.*<br>• *To take time to recover and connect with my baby once they have settled.* |
| *Leaving the unit to get a snack, use the bathroom or get some fresh air. Worried that if I step away something will happen as I won't be 'on watch'.* | • *When I can, choose a time to pop out when my baby is calm and settled.*<br>• *Collect information to remind myself that they are not more likely to have an incident when I step outside for a few minutes than if I was here, even if it can feel like the risk is increased.*<br>• *Work towards leaving them gradually – moving from a few steps away from the incubator to standing at the door, and then build up to stepping out of the nursery. Make a note of what happens.* |

Think about your own examples and what you can put in place. Sometimes these may involve very small changes or modifications to what already happens (such as someone talking you through continuously and calmly what the neonatal team are doing or looking out for during a procedure). Here are some questions to help you find some solutions and aid with planning:

- What made this situation easier to cope with/less anxiety provoking before? (Look for 'key ingredients', whether these are people, actions or other things)

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- What do I know about myself and how anxiety works for me that I can bring to this situation and let others know?

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- When do I find my anxiety perhaps in the same circumstances is reduced? What is different then, and what can I learn from that?

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## CONNECTING TO EMOTIONAL RESOURCES

Take a moment to make a note of what you feel you need in terms of connection to an emotional state, and when you might use it as a resource to help you. Add your own notes after the example.

| Situation | Emotional state memory resource |
|---|---|
| *Feeling anxious and ignored in the nursery – no one around to talk to.* | *Connecting to a time when I felt cared for and special with my grandma. Feeling the warmth of her presence and the smell of her kitchen.* |
| | |
| | |

## IDENTIFYING PEOPLE AROUND YOU WHO HELP YOU FEEL CONTAINED AND CALM

Have a look at Mary's example. You can add your own examples below Mary's.

| Person | Where and when can I see them? | How do they help? |
|---|---|---|
| *Mary* | *She's the unit cleaner, there every day on the corridors and by the lockers.* | *She always says hello with a big smile, she talks to me about her grown-up children and normal life. She helps me to feel calm and sometimes makes me laugh. The fact that she seeks me out and asks about baby Josh helps me to feel seen and cared for.* |
| | | |
| | | |

## CREATING A COMPASSIONATE COMPANION TO HELP AT TIMES OF DISTRESS AND DIFFICULTY[1]

The aim of this exercise is to create a sense of inner soothing and security via a perfectly compassionate companion who embodies all the qualities you would need from someone totally focused on your welfare.

Think about the *qualities* that this person needs to have. In addition to compassionate qualities just highlighted, add other qualities here that matter to you:

Other important qualities:

Think about what your compassionate companion would look like. Describe their physical appearance, thinking about how old they are, whether they might be a person, or perhaps an animal. Would they have a certain smell or a certain 'felt sense' that is unique to their presence? What would their voice sound like (soothing, calm, low or high, familiar)? You can be creative here, but take the time to really elaborate the image so that it feels as vivid as possible. If you have artistic talents, you may even wish to draw them in your journal or on a blank piece of paper:

1 This exercise has been modified from Deborah Lee (2012).

Think about where you would like your compassionate companion to be. They can be anywhere. You may wish to meet with them in a specific place that represents safety and calm, or you may wish them to be alongside you wherever you are. Take a moment to map this out:

How would they respond to your distress and experiences? When you are struggling with what is happening, memories or difficult emotions, what would your compassionate companion offer you by way of comfort? What might they do first? And then, what would they do next? What would they say to you? Jot down some of their actions and what they might say, including how they might say it (think about their tone of voice, emphasis and overall delivery):

## ENGAGING WITH YOUR COMPASSIONATE MIND

Take a moment to identify some of the thoughts you are experiencing, engage with your compassionate mind, and then see if you can write a compassionate response:

| My thoughts | Compassionate response |
| --- | --- |
| | |
| | |
| | |

## CONFIDENCE, MEANING AND CONNECTION IN CARE

Make a note of the ways you are starting to get involved in your baby's care. Here, we are going to consider three key areas:

1. How confident do you feel doing a particular care/activity?
2. How connected do you feel to your baby during this activity?
3. What does doing this task with your baby mean to you?

These will change over time, and sometimes it may be helpful to revisit this exercise to take stock of the things that may feel different over the weeks or months. You might want to make an additional note of what you need in each area to help increase your confidence, to make the activity feel more meaningful,[1] or to help you to feel more connected to your baby.

You can see Samir's examples below. Add yours. You may want to continue this in a notebook or shared document with your neonatal team.

| **Area of care** | **How confident and connected do I feel during this activity?**<br>**How does this activity have meaning for me?**<br>**What do I need to increase my confidence and/or help the task feel more meaningful?** |
|---|---|
| *Changing nappies* | *Quite confident now I know how to manage the wires. I prefer an extra pair of hands when my wife is there to help!*<br>*It helps me feel connected when I can get a bit closer and watch her face to see how she feels. She enjoys me talking to her too – she's definitely happier when I do it than a nurse.*<br>*This feels like it has meaning to me as it's something I would be doing if we were at home – a sense I'm able to do the basics of baby care as a dad.* |
| *Reading stories* | *Confident (when the nursery is quiet). It felt odd to start with – like my words were going into a void.*<br>*But I put my hand on her now when I am reading, which helps us feel more connected, and I've chosen a book that's meaningful for us.*<br>*Now it feels like I really want her to hear the words I speak because they are for her. I will read it to her when she's older too, and can really understand.* |

1 When using a word to describe certain interactions with your baby you may hear people use the word 'activity' or 'occupation'. Whilst these might seem to fit at certain points, there may be other moments where this feels like it doesn't quite capture the nature of what's taking place between you and your baby. You may want to experiment with the right vocabulary for you, and share this with others.

| | |
|---|---|
| *Talking with doctors about her care and what I feel she needs* | *Not so confident. I will ask for some more help with this as it always feels like I'm not the expert, that I wouldn't know. I sometimes feel I can feed back to the nurses about what she likes for her 'cares' – though sometimes I tell them things they don't know about her, which feels good! It means I can speak up for her little by little and be her voice.* |
| | |

## THINKING ABOUT THE IMPACT OF YOUR PREVIOUS RELATIONSHIPS

Take a moment to think about how your previous relationships and experiences with others may influence how you feel and act when you meet the clinical team on the unit. Notice that you may feel differently about different people or in different contexts. You may want to jot down what you notice here:

## WORKING OUT WHAT YOU NEED FROM RELATIONSHIPS WITH THE TEAM ON THE UNIT

Take a moment to consider the people around you and who your 'go to' people are. If your unit is large and you may often not see the same person, try to identify several people over time who might fulfil these roles:

- Who around me at the moment helps provide a sense of connection and safety?

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- Who can help me to feel more at ease and confident in caring for my baby whilst in hospital?

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- Who is a good person to go to if I have any worries or concerns or if I'm not having a good day?

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- Who understands me as a person?

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- Who can I feel more relaxed with and helps me feel like myself?

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- Who is a good advocate and someone who can support me to say what I want to?

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- Who supports and understands my spiritual and cultural needs best?

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## THINKING ABOUT AND PLANNING NEEDS IN EVERYDAY CARE

Take a moment to think about your day on the unit and consider the following areas that will help you plan with your neonatal team.

### Your baby's needs

You can think about your baby's needs in many ways as they uniquely develop as a little person, born to connect with you. First and foremost, they need contact with you to feel safe and secure, to develop and thrive. They also have a lot of work to do as they learn to breathe, grow, feed and recover from illness. Spend some time observing how they try and relate with you, and watch how this changes over time.

Your baby's behaviour is their way of communicating. They will show a number of behavioural 'cues' (which are a way of telling you something) during different activities or tasks (e.g., feeding cues or cues that show how overwhelmed, distressed or regulated and ready to interact they are). It can be helpful to make a note of their cues to share with everyone who looks after them as well as what helps (e.g., ways they are currently soothed, calmed and reassured). This means that they receive the benefit of consistent caregiving approaches when you aren't able to be with them. Update this regularly as they develop and change over time.

In the course of the day your baby may have programmes or exercises they might be doing under the instruction of an AHP or other health professional. They will need protected sleep and rest time. As they develop you can also add in their favoured activities, things they like to look at and listen to, as well as their preferences for touch and comfort.

My baby's needs:

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### Your needs and preferences

These can include practicalities such as when you are able to be on the unit, when you are available for the sharing of key information and ward rounds, and who you might wish to have with you for certain tasks or conversations.

Keela requested that her boyfriend was present if an important update was being given to support her and help process the information.

A key consideration over time is *when* you wish to be contacted – for example, when you want the unit to call, even if it's the middle of the night, what kind of things you are happy to happen or be decided in your absence, and when you would like to be asked if you aren't present.

Think about what your emotional needs are in the context of planning your day. Some might be easier for staff to spot and work around (such as breaks), but others might need to be made explicit (such as when you would like to spend time with your baby uninterrupted, or additional support needed at certain times of the day).

You might have additional communication needs or preferences that make a tangible difference to how the unit feels for you. For example, if you're neurodivergent, you are likely to encounter specific challenges on a neonatal unit. It's helpful to share these so that the environment and communication can be adapted or modified where possible. Specific learning difficulties such as dyslexia or language or auditory processing difficulties can also have a significant impact on how easy it is to navigate the neonatal experience, and add to distress and overwhelm if not addressed. As much as it can feel sensitive information to share, it ultimately means you are in a better position for the team to work with you when they know how to communicate, understand and help.

My needs and preferences:

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## What the needs are of you and your baby together, as a pair

Time for nurturing the relationship between you and your baby is important and can feel it has little space amongst all the tasks of the neonatal unit. Think here about what time you would like to spend nourishing you and your baby as a pair. This might mean scheduling when you can have uninterrupted time to get to know and 'tune in' to one another. You might want to talk with your nurse about the kind of things you can do with your baby during this protected time that are most important to you. Whilst it's not always possible to predict when your

baby may need medical intervention, discussing with the team if it's possible to cluster procedures or examinations so that there are protected periods of time can be helpful.

As your baby gets better you will have more opportunities to engage in interactions that feel more actively reciprocal (two-way), but don't be discouraged if it feels a little more one-sided to start with. Your baby might find engaging with you a lot to manage alongside all the other things they're dealing with whilst in hospital, and it can take time. Even when it feels like your baby might not be aware of your presence, remember that they already know you, and the early curiosity and interest in each other is a real investment for the future (you can read more about this in Chapter 5). This time doesn't have to look like you're *doing* a lot – being attuned to your baby and responding to them is an important use of time in and of itself.

My needs together with my baby's needs:

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## What your needs are as a family (parenting together, involving siblings, grandparents and elders)

If you have a partner, sometimes the time you have together with your baby is very limited as you juggle the demands of family and work outside the unit. However, many parents describe this as feeling like another loss if not attended to whilst in hospital, so it can be helpful to make some time to spend all together, making memories of your earliest times as a family. If you have other children, it can also be important to have regular family time when you're all together. Consider what would be most helpful if your time as a complete family is limited, and talk to your children about what they'd like to do with their brother or sister. This can be particularly important for family milestones that you want to mark in a special way.

Lottie's fifth birthday was an event the whole family had planned to celebrate before the early arrival of her sister Jane. By letting the unit know this was a key event, they were able to decorate the incubator to help Lottie feel like her baby sister was part of her special day.

Grandparents are also significant members of many families, and for some parents they are vital emotional and practical supports. If you have parents or other elders in your life who hold this kind of significance for you, FiCare includes them too, according to your wishes and preferences. Let your neonatal team know about how you would like them to be involved and be able to support you. The neonatal unit can be distressing and overwhelming for grandparents and other family members, and whilst their focus is likely to be on supporting you, if they would benefit from having a conversation about their own needs, charities such as Bliss[1] can help.

Our needs as a family:

1 www.bliss.org.uk

## YOUR ROLES AS A PARENT

Think about these roles and how they fit with your experience. Write what's most important about your experience so far here:

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List other parenting roles that are important to you here:

1. .....
2. .....
3. .....

## YOUR JOURNEY INTO PARENTHOOD

As you read about these parents' different situations and journeys, take a moment to think about your own journey and story.

What's important to you about what you were hoping for or expecting? What's different and what's the same between you and your partner? Make some notes here about what matters most about your journey into parenthood:

## TAKING STOCK OF SIGNIFICANT LOSSES AND THEIR MEANING FOR YOU

Think for a moment about some of the losses you have experienced as an individual and as a family. Make a list here of these:

## UNDERSTANDING WHAT SHAPES YOUR THOUGHTS, FEELINGS AND BELIEFS ABOUT BECOMING A PARENT

When thinking about how you feel at this moment in your parenting journey, consider your experiences in society, your culture, your religion and your family and friends in terms of how they have shaped your thoughts and feelings and beliefs:

- Pre and during pregnancy (including previous babies, if applicable)
- Experiences around birth
- Having a baby in neonatal care.

You might want to consider what messages they have given you (e.g., society can give a message that new parenthood is a wholly happy time or your family may have been an environment where distressing feelings or ambivalence about becoming a mother were unspeakable). As a child you may have experienced love and having your needs met, or perhaps you felt neglected or ignored. You may find that there are multiple messages or experiences in each area, reflecting the complexity of our lives.

Take a moment to think about your experiences and what messages you have been given in each of these areas. Short examples are included in the table to help start you thinking, **with some space to write about yourself underneath:**

| | **Pre and during pregnancy** | **Experiences around birth** | **Having a baby in neonatal care** |
|---|---|---|---|
| Society | *The main message was feeling like I had to be happy and feel lucky I was having twins.* | *I was told I should 'hold out' for pain relief as it would reflect badly on me if I had it too soon. When it happened I was in such pain and thinking I was a failure because I needed an epidural.* | *I can't see my experience of neonatal care reflected anywhere I go – it feels like I have a secret!* |
| My experiences | | | |

| | | | |
|---|---|---|---|
| My culture | *The main message was I had to be strong and brave at all times. I have seen other members of my family really struggle with this – feeling ashamed and having to hide what they're going through.* | *My 'take home' was it's just what you have to go through – if it's hard, don't make a fuss – generations of women have done it without complaining.* | *I have to be strong otherwise it will affect the babies – it's hard to feel like I could be damaging them if I cry or feel overwhelmed.* |
| My experiences | | | |
| My religion and/or beliefs and values | *There is a definite sense that babies are a gift from God – this feels true and I am grateful, but it also left no space to say things weren't easy, like on the days when I felt so sick I wished I hadn't got pregnant.* | *I believe God will protect them and me – whatever happens is his will.* | *I must pray for their protection, and God won't give me more than I can handle.* |
| My experiences | | | |

*cont.*

| | | | |
|---|---|---|---|
| My family | *They are supportive and excited about the babies, but I have never felt like they want to hear what things are really like for me emotionally. I feel like I have to keep them happy by always being happy. As a young child I felt invisible. I learnt very quickly my feelings weren't important to them.* | *Everyone wanted to be at the birth – I know they meant well, but there was little space for my own opinion. When I told them I only wanted my husband with me, they were offended and I felt guilty and upset.* | *The message I got was they'll be fine if I pray hard enough. I'm almost not allowed to think about any other outcome or express my fears, so I keep them to myself at the moment, just as I did as a kid, but I might talk to the chaplaincy team next time they come by.* |
| My experiences | | | |
| My friends | *My friends have always been a huge support – they come from all backgrounds and accept me as I am. They could hear I was a bit nervous about having twins – and the message was that's okay, that it's normal to feel apprehensive about becoming a mother.* | *A few of them had given birth already – they told me how it was for real. I valued their honesty.* | *They told me I could call them any time, and I do. They are always on WhatsApp sending me messages, and often surprise me by coming to the hospital to accompany me on the way home.* |
| My experiences | | | |

When you look at your responses for each of these areas, take a moment to pause and take stock. You might want to consider:

- Are there particular things that have come to light doing this exercise that are new, validating or helpful?

- Have you found yourself making any connections between the messages and experiences you have had in your life and what's coming up for you as you become a parent? If you have had a baby before, are there any differences this time? Are there things that you notice from your own experience of being parented as a child that arise for you?

- Notice how completing this exercise has made you feel about yourself. Do you notice any criticism, minimizing of difficult experiences or perhaps some compassion and kindness towards yourself? Are there things you are proud of or that give you a sense of achievement?

## MAPPING OUT DIFFERENCES BETWEEN NON-NEONATAL AND NEONATAL EXPERIENCES IN EARLY PARENTING MILESTONES

Some differences in non-neonatal and neonatal experiences parents often highlight as significant are outlined in this table. **There is also space for you to add experiences that you feel significantly differ and matter to you, and that might be shared and that might be the same for other parents in the unit.**

| Non-neonatal experiences | Neonatal experiences |
|---|---|
| *Birth of baby followed by immediate access/ access within hours to baby.* | *Birth of baby where there's often only brief contact before long period/s of separation.* |
| *Choice of clothes to dress baby, blankets, feeding preferences.* | *No/few choices in early care or space to express parenting preferences.* |
| *Easy access to pain relief, food and medication.* | *Access to pain relief, food and medication can be restricted or challenging.* |
| *Partner's/other children's/extended family's access to mother and baby (some variation post-Covid-19 across hospitals).* | *Extended family and siblings often have restricted access.* |
| *Discharge typically within 48 hours.* | *Often facing long period of admission to hospital, variable facilities for parents and can be far from home and support systems.* |
| *Immediate responsibility for baby including decision making and preferences given to parents.* | *Immediate need for medical care from professionals and immediate decision making often made in the absence of parents or with limited input in baby's best interests.* |
| *News of arrival shared rapidly with friends and family.* | *Often difficult decisions about what news to share with whom and when.* |
| *Cards, presents and congratulations given from friends and family.* | *Friends and family often uncertain of what to say or how to respond.* |

| My own previous experiences outside of neonatal care and/or those I had hoped for | My neonatal experiences |
|---|---|
| | |
| | |

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As you look back at this list, notice what this brings up for you emotionally, without judgement. It's important to compassionately acknowledge the losses, disappointments and changes that you have been through as a result of your baby being admitted to neonatal care.

As you acknowledge these, you may feel a range of emotions. Take a moment to make a note of these here:

## REVISITING PARENTING ROLES ON THE NEONATAL UNIT: 'WHICH MATTER TO ME MOST RIGHT NOW?'

The parenting roles we thought about in Chapter 4 included: guardian, protector, encourager/cheerleader, holder of hope, nurturer, comforter, observer, advocate and ally and delight-taker. You may have added some of your own too.

Think about what roles matter most to you right now and why, and write them in the table. *This will help you to focus on what you can do, even when there can be a lot of things you feel you can't yet do*.

If you have a partner, you might want to do this exercise together and think about the answers for both of you. What is similar and what is different? How can you develop an understanding of each other's parenting journey to help you grow together?

| Role | Why it matters to me |
|---|---|
| *For example, Advocate* | *For example, I grew up learning to speak up if something wasn't right or needed to change. I feel this is something I can do straightaway for my son.* |
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## EXPLORING HOW YOU FEEL ABOUT YOUR BABY

As you read these stories, take a moment to think about how you feel about your baby.

What kind of thoughts or feelings come up for you? As you notice them, try to capture what goes through your mind as well as what you might feel in your body without judging it. Just be curious about what's there right now, and make a note of it here:

## WHAT IMPACTS YOUR SENSE OF CLOSENESS AND CONNECTION TO YOUR BABY?

In addition to these experiences listed above there will be other factors that can have an impact on your sense of closeness and connection. Take a moment to list any others that you feel are relevant for you here:

## RECORDING 'MICRO MOMENTS' WITH YOUR BABY

We can often miss the small ways that tell us a connection is beginning. How do you feel when you leave your baby (e.g., feeling a physical change or that something is missing)? Do you think about them when you're not with them (such as wondering what they might be doing or who is looking after them)? Do you have any moments, even if they last only a few seconds, when you experience a feeling of love or pleasure?

Make a note of these moments when they happen and how they feel. Extending our gardening metaphor, keep a record of the 'buds' that start to emerge. They may not be big moments, the grand flowers or blooms, but they are still important and will accumulate over time.

## EXPANDING A 'MICRO MOMENTS' LIST TO ENCOMPASS MORE ABOUT YOUR BABY AND YOUR CONNECTION WITH THEM

There is an opportunity to extend the use of diaries or positive micro moments logs to help consolidate your moments of connection and to develop a map of your baby over time as they change and may feel more like a little person.

Other areas you could consider keeping a record of include:

- Moments when they feel very much like a baby and/or feel like *your* baby.

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- Moments when you notice them responding to you specifically – what do they do and how do you know?

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- Activities or moments where you feel more of a connection (and ones you might like to try).

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- What kind of characteristics they have now or are developing – glimmers of their unique personality or physical appearance, for example.

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- What soothes them and helps them to feel safe and secure.

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- How do they communicate with you? What are their cues and what do they mean? Have they changed over time?

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What other things would you find it helpful to keep track of with this connecting focus?

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What things help you to feel like your baby is a unique person? Make a note of them here:

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## QUESTIONS TO BUILD A SHARED UNDERSTANDING OF EMOTIONS WITH YOUR CHILD

Sometimes the way we ask questions can help children express and articulate what they feel in ways that make sense to them. These questions help you and your child to build a shared understanding of their experience. Summarize back what they've told you or drawn for you so they can experience being heard, seen and understood, e.g., 'I can see that this feeling coming up is really big, it feels really dark and spikey, like a hedgehog'.

If there are other questions or phrases that have worked well with your child/children, add them here for reference:

- How big is this feeling? (Huge – takes up all my body/bigger than me, or smaller?)
- Does it have a colour? (Explore why it has that colour, it is red because it feels hot, for example.)
- Does it have a shape? (Is it spikey or heavy or cold?)
- Where do you feel it in your body?
- Does it have a name? (It can be a made-up name or the name of a person or animal.)

### Questions to help you find a way to manage feelings together

Creatively using questions can help you find solutions together. Once you've understood how they're feeling you can start with some general questions linked to what they tell you. You may want to make their answers into a plan that they can feel part of. Check in every few days to see how it's working and if you need to make any changes.

Jot down some questions you may also use with your child here, and any other notes that might help you make a plan together:

Here are some examples of questions you could use when being curious about feelings and experiences with your child:

- What makes/when does the feeling grow bigger/darker/heavier?
- What makes/when does the feeling become smaller?
- Is there something we need to do with this feeling together?
- What can prevent it from getting bigger?
- How can we help it to become smaller?

## QUESTIONS TO ASK WHEN THINGS MIGHT FEEL OVERWHELMING FOR YOUR CHILD

- What would you notice first if your jug was becoming too full?

- What would mummy or grandad (for example) notice?

- What could you do to help straightaway if you noticed one of your signs that your jug was becoming too full (e.g., heart racing, crying a lot, feeling angry all the time)?

## USING EMOTION SCALES TO HELP FIND SOLUTIONS

Once you have some understanding of your child's emotional experiences, use one of the number scales to map out what each stage of the scale would look like for them. Starting at 10/10, explore what this would feel like for them and how others would know. Do the same for each point on the scale. You then have a shared 'shorthand' for assessing where they're at.

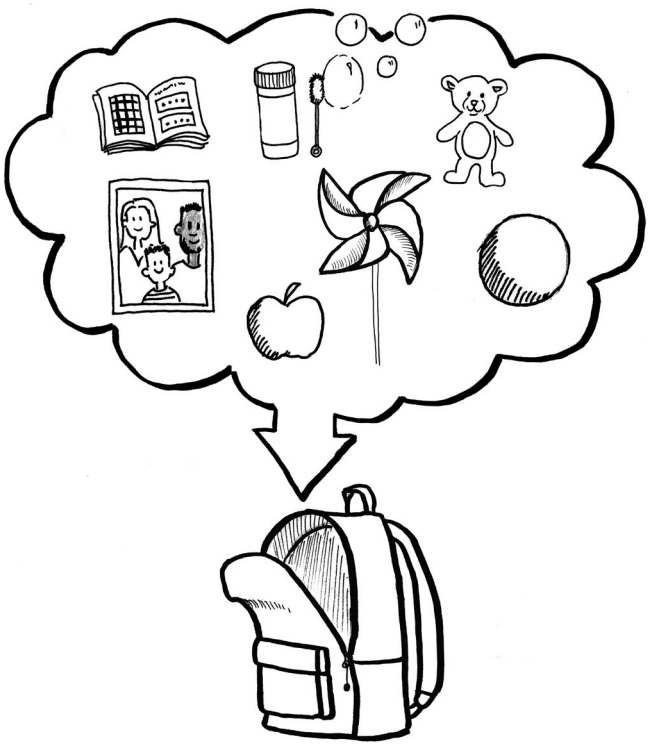
Given there are many times when it's not possible to take away the feeling completely, scaling helps them to realize feelings aren't 'all or nothing' and that small changes can be helpful.

See how Anish and his dad used his worry scale to help think of some practical steps to help in the following example.

## MAKING A FEELINGS KIT BAG

Explain to your child that this bag can stay with them, and help them to remember what each item is for. It can also be helpful to have a guide card for teachers and other caregivers so they can help them to use the contents most effectively. Here are some examples:

- Squeezy ball for when I'm stressed.
- Photo of me and my mum and dad for when I'm sad.
- Small teddy to cuddle with mummy's perfume on if I'm missing her.
- A book of puzzles to help me re-focus and feel calmer.
- My favourite snack that feels familiar and comforting.
- A souvenir from my holiday to remind me of fun and happy times.
- Bubbles to help with my soothing/calm breathing.



*A 'Feelings kit bag' for children*

## CREATING AN IMAGE OF A SAFE/HAPPY/ CALM PLACE WITH YOUR CHILD

Invite your child to imagine a place that helps them to feel safe, happy or calm. Ask them if they can travel there in their mind and describe it to you, including what they can hear, see, touch, smell or even taste. They can decide if they want other people to be there, or certain animals or pets. You can encourage your child to include real or imagined places, people and animals in their created place. The aim is for them to include whatever they need so that it helps them to experience a helpful change in their emotional state.

Encourage them to 'take a photo in their mind' once they have been through the exercise, or they may wish to draw it or find an object that represents it. They can put this object or drawing in their feelings kit bag, or put it up on a wall at home.

## REFLECTING ON THE DECISIONS YOU'VE MADE SO FAR

Take a moment to reflect on the decisions you have made up to this point. You might want to consider some of these questions:

- What was making the decision/s like for you?
- Were there some that were harder than others?
- To what degree do you feel those decisions were shared with medical professionals and your family/friends, and to what degree do you feel you made them on your own?
- Did you feel like you had what you needed to help you make those decisions, and if not, what would that have looked like?
- What would have made the process of making those decisions easier?

Make a note of some of your responses and thoughts here:

## ‘TUNING IN’ TO WHAT YOU NOTICE IN YOURSELF WHEN YOUR BABY IS IN PAIN

Spend some time tuning in to what comes up for you when you see your baby in pain:

## ✓ WHAT WERE YOUR HOPES AND EXPECTATIONS FOR YOUR BABY?

Honestly and without censor think about what your expectations and hopes were for your baby. Then take a moment to go down your list and acknowledge how you feel about these expectations and hopes at the moment and what comes up for you. Here are a couple of examples from Danya, and some space afterwards to add thoughts of your own:

| **Expectations and hopes** | **How I feel at the moment** |
|---|---|
| *Having a child who would look like me and people in my family.* | *I can't see anything of myself in her – I keep searching, but with no success. She doesn't feel like mine.* |
| *I hoped that she would be able to run around with other children at nursery and make friends.* | *I'm worried she won't be able to enjoy life. I can't imagine how it might be in school – will she make friends and be able to join in? It feels devastating.* |
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You may wish to do this exercise with your partner or other significant family members. Give space and time to each other to be able to express how you're feeling without judgement.

## MAPPING MEANING, THOUGHTS AND FEELINGS

This exercise invites you to consider a series of questions about what it means to you to have a child with a long-term medical condition or disability. As in the previous exercise, try not to censor these thoughts as they arise – the point of the exercise is not to evaluate them or judge, but to give yourself permission to express them honestly and openly. You may want to imagine doing this in the presence of your compassionate companion or other resourcing figures from Chapter 2, or make your way through these with a partner or other loved one.

- What thoughts or beliefs do I hold about why this happened to me and my baby? What does it mean to me that it has happened?

- What does this mean about me and my life?

- What are my biggest fears and worries right now?

- What worries and thoughts do I feel I can share, and which ones am I keeping to myself?

- What fears, worries or disappointments do I have that relate to things that might happen (or not happen) in the future?

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- What emotional impact is this having on me now? Are there any fears I have about the emotional impact in the future?

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- What impact will this have on my relationships with my children, partner, friends and family? Are there any specific worries about these?

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## EXPLORING THE IMPACT OF YOUR BABY'S LONG-TERM HEALTH CONDITION/DISABILITY ON YOUR PERSONAL AND PARENTAL IDENTITY

Take a moment to list the ways that you feel your baby's diagnosis has impacted your personal and parental identity. You may wish to come back to this at various points in time to see what may have changed and what has contributed to those changes:

## THINKING ABOUT HOW YOU VIEW YOUR BABY'S IDENTITY

Take a moment to think about the journey of your baby, and jot down some of the words that come to mind:

## THINKING ABOUT SUPPORTING YOUR BABY AND THE STORY THEY DEVELOP ABOUT THEMSELVES

Here are some questions to ask yourself about your baby. You may want to return to these at different time points as they grow. You may also wish to share these questions with your partner, family member and other people who have a key role in shaping their world:

- What is important for them to know about themselves?

- What's the story you would like them to hear about their journey so far?

- How would you like them to feel about their medical condition or difference?

- How can you show them what they mean to you?

- How can you support them best, even when you may be struggling yourself?

- How can others around them support you to support them?

## QUESTIONS TO ASK YOURSELF AND DISCUSS WITH OTHERS: WHAT MATTERS AND WHAT'S MEANINGFUL?

- What matters to me as a parent right now, and what might matter in the future? (Think back to the parenting roles and values you have identified previously (in Chapter 4, 'Will my baby think of me as a nurse and not a parent?', and Chapter 5, 'Identifying what your values are as a parent and putting them into action') to help you.)

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- When you think about the future, what would you want your baby to have experienced and known about your thoughts and actions (e.g., 'That I explored every option for you', 'I was with you when you needed me')?

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- How do you want to be there for your baby now? What helps you to be able to do this? Who do you need around you to help, and how? What journey do they need to go on, and how can you help them to make it?

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- How do you want to weave your baby into the landscape of your life and others in this period of time? (This can be through the experiences they have with others or particular places or activities. You may wish to ask grandparents and siblings what this would look like for them in terms of meaning and significance. For some it's grounding and comforting to consider intergenerational traditions, stories and rituals they would like to incorporate. How will your baby always be part of those? For others, it's about creating new and meaningful traditions, stories and rituals.)

## YOUR BELIEFS ABOUT DEATH AND DYING

- What do I believe happens in the process of dying and afterwards? Knowing this, what's important for me, my baby and others?

- What absolutely *must* happen in this process? And have I let the team caring for us know?

- What are my wishes for what happens before, during and after death?

- What do the team need to understand to help me best in line with my beliefs?

- Who else needs to be here to be able to help this take place?

## YOUR FEARS AND CONCERNS ABOUT THE FUNERAL

Take a moment to think about what your own fears or concerns are about your baby's funeral. These may be general or very specific based on your own life and circumstances:

## IDENTIFYING PARTS OF YOURSELF AND THEIR NEEDS

After Martha's example, there is space for you to add your own words.

| Part of myself and emotion | What that part of me needs |
|---|---|
| *Grieving part: full of sadness, unable to focus, chest feels hollow, don't know what to do next.* | *Comfort, reassurance, no judgement about how I am, physical closeness.* |
| *Angry part: raging at the injustice of the situation, angry at people whose babies are okay, angry at still having to come to the hospital.* | *Understanding: listen to me, hear me out; help me to know it's okay to feel.* |
| *Fearful part: scared about being able to leave my other baby, scared they will die too, scared to know how to be in the world with all this grief.* | *Patience. Don't minimize my fear, don't tell me it's all okay when it's not. Help me learn when it's safe, show me what I need to see to feel differently.* |
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## IDENTIFYING HOW YOU FEEL ABOUT GOING HOME

Take a moment to listen in to what is happening for you emotionally as you think about going home. Give yourself permission to let any feelings come up, without judging them if you can. If you do notice a critical voice or a judgement about how you are feeling arise, just acknowledge that that is there, too, as part of the here and now. Write down some thoughts here.

## MAKING A GOING HOME PLAN

Here is an example of some of the areas and questions to think about. You may want to work on this plan with your partner or close friends to look at what needs you have in common and those that could differ as well as adding to it as you go along.

- What are my needs practically in the next few weeks?

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- What do I want to happen most when we are home? Are there any barriers to this that need addressing (e.g., managing the expectations of family visits, childcare)?

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- What am I most worried about? Is there a way to address some of these worries?

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- What am I looking forward to, and how do I make time and space for this?

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- How would I know if I wasn't coping? What would I notice first? What would others around me notice and need to look out for?

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- Who do I need around me to support me and how? (Gather contact details and put them in an accessible place.)

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- What's most important for healthcare professionals to know about me and my baby?

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- If there are carers coming into my home, what do they need to know about how we live, the way we parent our baby, how we wish them to be cared for and how we can work together?

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- What matters most to me in this next period of time?

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## ✓ WRITING A LETTER TO YOUR BABY: 'WHAT I WANT YOU TO KNOW'

This can be a powerful exercise at this stage in your journey, as you reflect on what's important for your baby to know. You may want to include some of the following sections in your letter:

- What happened to you
- How I cared for you
- How people helped
- What you taught me
- What I know now
- What I want you to carry with you
- How I want our future to be.

List other things you wish to include here:

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Once you have completed your letter, it can be powerful to share it with your baby by reading it out loud. As they get older, you may want to choose a moment when they can understand it to share it again and what they mean to you.