



Chapter 13. Coping in the NICU

Parent educational material for App

1. Coping in the neonatal unit

You are your Baby's most important resource, so it is important to attend to your wellbeing, recovery and resilience as you take on the parenting role in the neonatal unit.

This chapter will introduce you to common emotional experiences that may arise for parents when your Baby is in the neonatal unit. We hope this will help you – and those who know you – understand that a wide range of emotional reactions is normal. We will also share ideas from other parents about the skills that they found helped them cope, and guide you to identify your own best coping strategies.



There is also specialist support within the neonatal team from our clinical psychologists, as many people find that it is in talking through their own individual situation that they find their own way to cope with the situation.

Babies are social creatures and require one or two consistent loving caregivers to grow and thrive in all aspects of their development. They are also resilient and flexible and able to be looked after by others (for example, while you recover from birth, take breaks during the day or need to go home to look after other children). However, it is the parent figure – who comes back day after day, gets to know them in every little way and responds to their needs with love, enjoyment and predictability – and it is you as a parent who the baby will become attached to over their first year of life, preferring you to all others.

Babies form this special attachment individually with the small number of people who are their daily carers (eg Mum, Dad, grandparent) and these relationships help them feel safe, be soothed when distressed, and have the confidence to learn and develop and begin to explore the world around them.

Parenting is an emotional journey: love is at its heart, and babies can only communicate emotionally and through their behaviour rather than in words and logic. All mothers experience a sudden change in their hormone levels after giving birth and this can be experienced as the 'baby blues' around day five. It is normal to find yourself (or your partner) unusually emotional and tearful around this time. It is part of a healthy adjustment and may give you the opportunity to begin to make sense of what happened around the birth which may have been sudden and unexpected. Accept the feelings that emerge and find someone sympathetic and who you feel comfortable with to help you begin to put your feelings and thoughts into words. Feel free to allow yourself to cry: tears will usually come and go, and can help release tension. If you do not wish to cry when you are with your Baby, then allow yourself time and space away from

them to be with your feelings, before returning to be with your Baby and finding little ways to be together that provide comfort for you both.

Aims for this chapter

We want you as a parent to:

- understand the normal range of reactions and parent experiences when your Baby is admitted to a neonatal unit
- know what resources are available to support your wellbeing as a parent during this challenging time
- learn about communication
- learn coping tips from other parents for you and your wider family
- identify the coping strategies that work best for you.

1.1 Parents' experiences of stress and coping in the neonatal unit

During pregnancy, you will have begun to imagine your new life as a parent of your Baby. When your Baby is admitted to a neonatal unit, you are likely to feel that much of what happens is different from what you expected. This can be hard to adjust to, and you may feel sad about what has not been able to happen or angry at how things have turned out.

The neonatal environment is likely to be unfamiliar with all its technology and can seem daunting. Neonatal teams are large, as staff is needed to look after babies 24 hours a day, seven days a week. You may suddenly find yourself having to get to know and interact with many different people, when you may have been expecting to spend this very special time after birth in the privacy and relative quiet of your own home.

You may initially be physically separated from your Baby, and this can be one of the hardest aspects to cope with, as you are biologically and socially primed to be with them, responding to all their needs. This separation of a parent and their newborn baby naturally gives rise to anxiety, as your instincts are telling you that your Baby needs you.

If you are not given the opportunity or ideas as to how you can still be with your Baby and be involved in meeting their needs in the unexpected world of the neonatal unit, it can be natural to feel helpless and if this is not addressed, in turn is likely to lead to you feeling low.

In [Chapter 5 'Working together as a team'](#) and in our [Developmental timeline](#) you can find tips and guidance on how to get involved in your Baby's care.

1.2 Communication: what supports good communication and overcoming common challenges

Communication works best when we all take time to get to know each other a little. You can expect staff to introduce themselves by name, and tell us your names too.

Taking time to chat and exchange ordinary social pleasantries allows us to feel comfortable with new people and builds trust and mutual understanding as a good foundation for more technical or challenging topics.

Do let us know more about yourself outside of being a neonatal Mum or Dad. What skills do you use in your work? What are your preferred ways of learning (eg reading, observing, learning through doing)?

Who else is in your Baby's family (eg siblings, grandparents)?

Share any questions or concerns with us – we may be able to help.

Some people like lots of detailed information; others prefer to know only what they need to know right now. Think about what kind of information seeker you are, and let the team know.

The neonatal team is large and getting to know and communicating with so many new people may feel like hard work at a time when you are under stress. You will gradually get to know the team especially those who work regularly with you and your Baby.

Neonatal staff often appear very busy to parents who feel hesitant to interrupt them with questions. However, communicating with you is one of the important tasks on their to-do list! So look for your moment, and if a member of staff is occupied with another task right now they should be able to come back to you later, or find someone else to deal with your concerns.

There is a lot of information on the internet. We prepared this material to give you relevant and accurate information about neonatal care. Do check any other information you come across with the neonatal team who can help you understand and apply it to your individual Baby.

In any complex communication and long-term relationship there may be moments of misunderstanding or differences of opinion. Try and resolve your concerns with the member of the team when they arise if you feel able. You can also talk to the nurse in charge, the consultant or a clinical psychologist or family liaison nurse. All hospitals also have a Patient Advice and Liaison Service who can support you if you feel you have not been able to resolve a concern with the team, and if needed they can advise you on how to make a formal complaint. See [Chapter 5: Working as a team together](#) for details on how to make a complaint.

1.3 Your Baby as a communicator

Obviously babies cannot talk, but we are all born as social creatures primed to interact with our environment. Words are only a small part of how even adults communicate – think how much you take in from people's facial expressions and body posture. You can see this when reflecting on how face-to-face communication is more valuable than telephone communication. Adults like to video call, particularly with loved ones.

As a parent your loving curiosity leads you to watch and notice subtle changes in your Baby's position, facial expressions and movements and wonder about what they may be telling you about how they are feeling.

Notice how your Baby responds to changes in the environment. Do they open their eyes when you begin speaking? Do they startle when a loud noise is made nearby?



As your Baby matures, they will have periods between sleep when they are awake and settled in a quiet, alert manner. This is the time when they will be most responsive and interested in looking at your face. They will listen intently to you talking and singing to them. When they yawn or look away they may be saying, 'thank you Mummy and Daddy for chatting with me, I'm a bit tired now'. You can help them settle into a comfortable position. You can read more about these developmental changes in [Chapter 12 'Developmental care'](#) and in our [Developmental timeline](#).

Skin-to-skin cuddles are a very physical mode of communication. Your Baby shares your sensory environment, enjoying your familiar smell, gentle and warm touch and the way your body can shift in response to their comfort needs. Your Baby's breathing rhythms and heart rate communicate with your own and settle into a relaxed pattern that supports growth and development. You can read more about the benefits of skin-to-skin in [Chapter 12: developmental care](#) and in the Bliss 'skin-to-skin' leaflet in your welcome pack.

It may be helpful to read the Bliss 'Look at me – I'm talking to you' leaflet. Staff can give you a copy or you can download it from the Bliss website (https://shop.bliss.org.uk/shop/files/Lookatme-I_m talkingtoyou.pdf).

1.4 Support in the neonatal unit

The whole team is here to support you in your parenting role and will be interested to know how you are getting on with recovering from the birth, coping with the emotional ups and downs, understanding your Baby and the care they require, managing home responsibilities etc.

Please let any of the team know if there is anything we could be doing to support you more, for example, giving you more information, comfort or privacy.

In [Chapter 5 'Working together as a team'](#) you can find more information on how to get more support.

Bedside nurse and neonatal team:

Your Baby has a dedicated bedside nurse all the time; they will work with you closely and be your first contact with the team. You can begin by speaking with your Baby's dedicated nurse. You can also speak with the nurse in charge or the medical team. We welcome your feedback.

Integrated Family Delivered Care coordinator

We have a dedicated nurse working on the Integrated Family Delivered Care Project. They coordinate the parent education sessions, provide one-to-one training as needed and support you in the discharge planning. If you prefer, you can approach them with your question or concern.

Psychology team

We have clinical psychologists on weekdays; feel free to talk to them at any time. They support the psychosocial and emotional needs of families and can offer support as required. Meet them on the ward, at parents group or ask a member of the team to arrange an appointment.

Parent group

The weekly parent group is a chance to come together with other parents, a nurse and psychologist to talk about life on the neonatal unit, and ask questions large and small about having a baby in hospital.

You can share any concerns that you have not had the opportunity to raise or resolve on the ward. Feedback forms are available for you to give us written feedback about any aspects of care that you have found supportive or ways in which you think we could improve our service to better meet your Baby's and family's needs. After you leave the unit, you may be invited to other forums to feedback your experiences and help us continue to develop our service.

1.5 Support for fathers*

In your new role as a Dad, you will experience a range of emotions surrounding the birth of your Baby. This journey in the neonatal unit is very different to how you imagined and planned fatherhood to be.

If your Baby or partner requires on-going medical care, you may find the experience overwhelming. The birth of a premature or sick newborn can be especially hard for new Dads.

You may be intensely worried about your Baby and partner and feel frustrated and helpless that you can't do more, while also trying to juggle work commitments and perhaps looking after other children at home.

Men often carry their fears and concerns on their own. You don't have to cope on your own. Do not be afraid to ask questions, show your emotions or ask for help. Family, friends, nursing staff and our psychology team can help you on this difficult journey.

It is helpful to remember that you are a very important part of the team contributing to the care of your Baby and there are many ways in which you can be involved. In [Chapter 5 'Working together as a team'](#) and in our [developmental timeline](#) you can find tips and guidance on how to get involved in your Baby's care and in [Chapter 9 'Making milk for your Baby'](#) there are some practical suggestions on how you can help support your partner to feed your Baby.



***Adapted from FICare Programme, Mount Sinai Hospital, Toronto, Canada**

1.6 Siblings in the neonatal unit

Having a new baby cared for in the neonatal unit will affect the whole family, including brothers and sisters. This information was prepared to help siblings in this situation.

Neonatal units have different policies about how siblings can visit and be involved with the new member of the family. We feel that their involvement is very important. Check with our team how siblings can visit their new brother or sister. When children are visiting the neonatal unit, talk to them about the importance of washing their hands and good hand hygiene to protect their brother or sister.

Our psychology team can give you support on how to explain what is happening to young children and how to facilitate bonding.



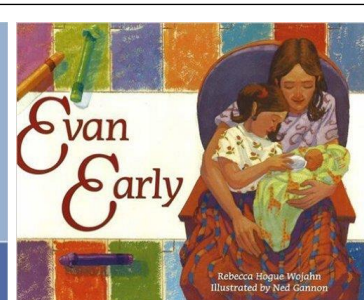
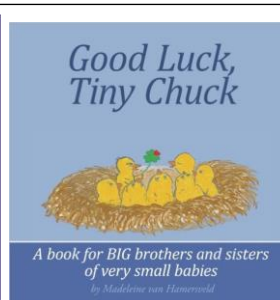
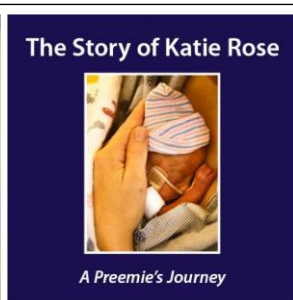
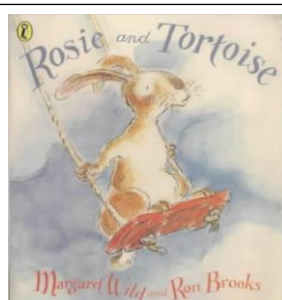
The experience of this stressful period in the neonatal intensive care unit (NICU) can be made easier for children if they understand what is going on. The 'Baby's Come Early' booklet was written by our veteran parents to help families in similar situations.

Baby's come early booklet

'Baby's come early' was written and illustrated by Julie and John O'Sullivan after having their premature baby, George. He was looked after by the team at Queen Charlotte's & Chelsea neonatal ward; the book is George's way of helping young children who suddenly find they have a baby sibling in a neonatal unit understand what is happening, and why.

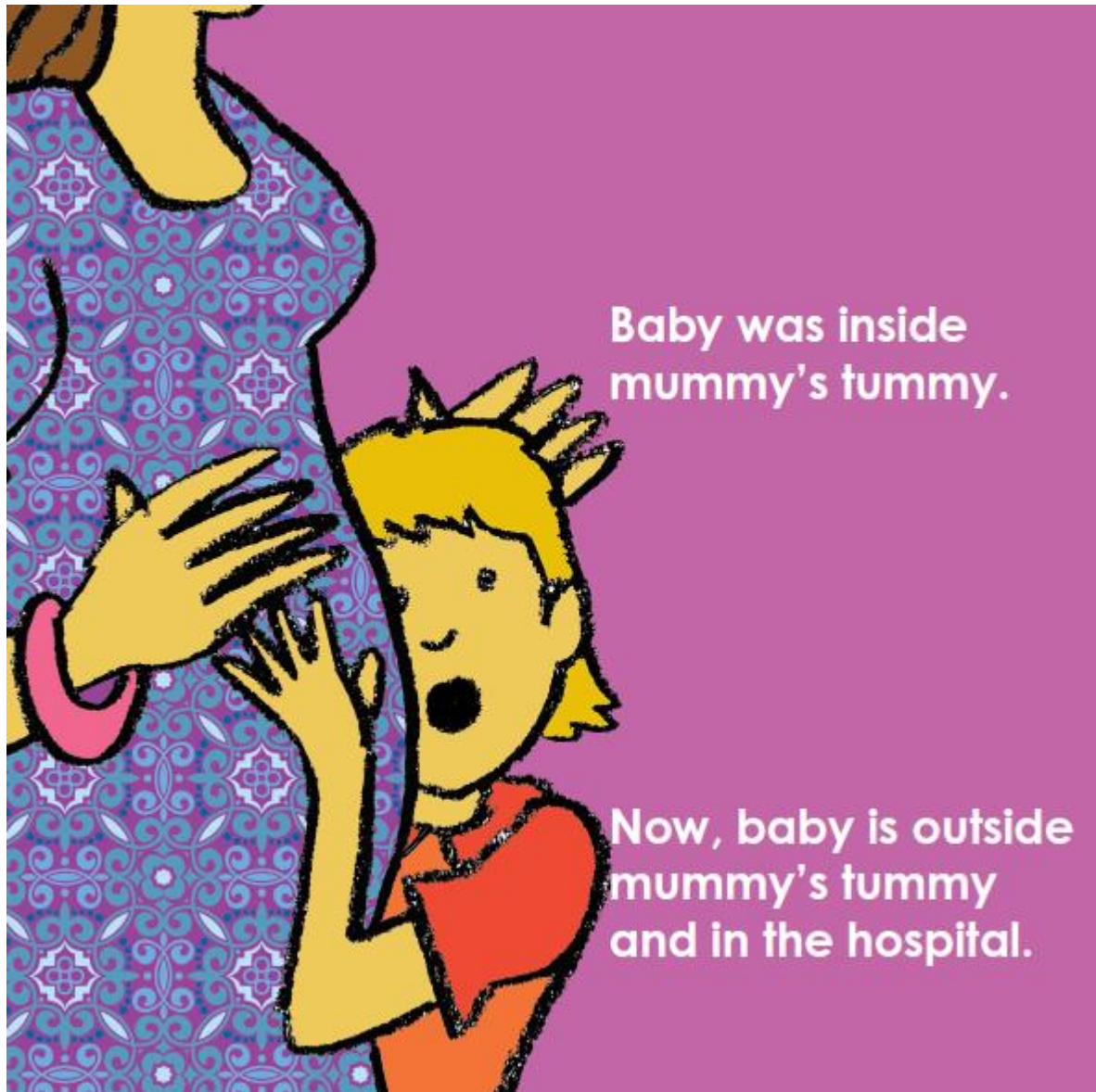
Other books for siblings:

Margaret Wild, Ron Brooks (2001): Rosie and Tortoise.
Harold and Phyllis Davis (2011): The Story of Katie Rose: A Premie's Journey
Madeline Van Hamersveld (2011): Good Luck, Tiny Chuck
Rebecca Hogue Wojann (2006): Evan Early



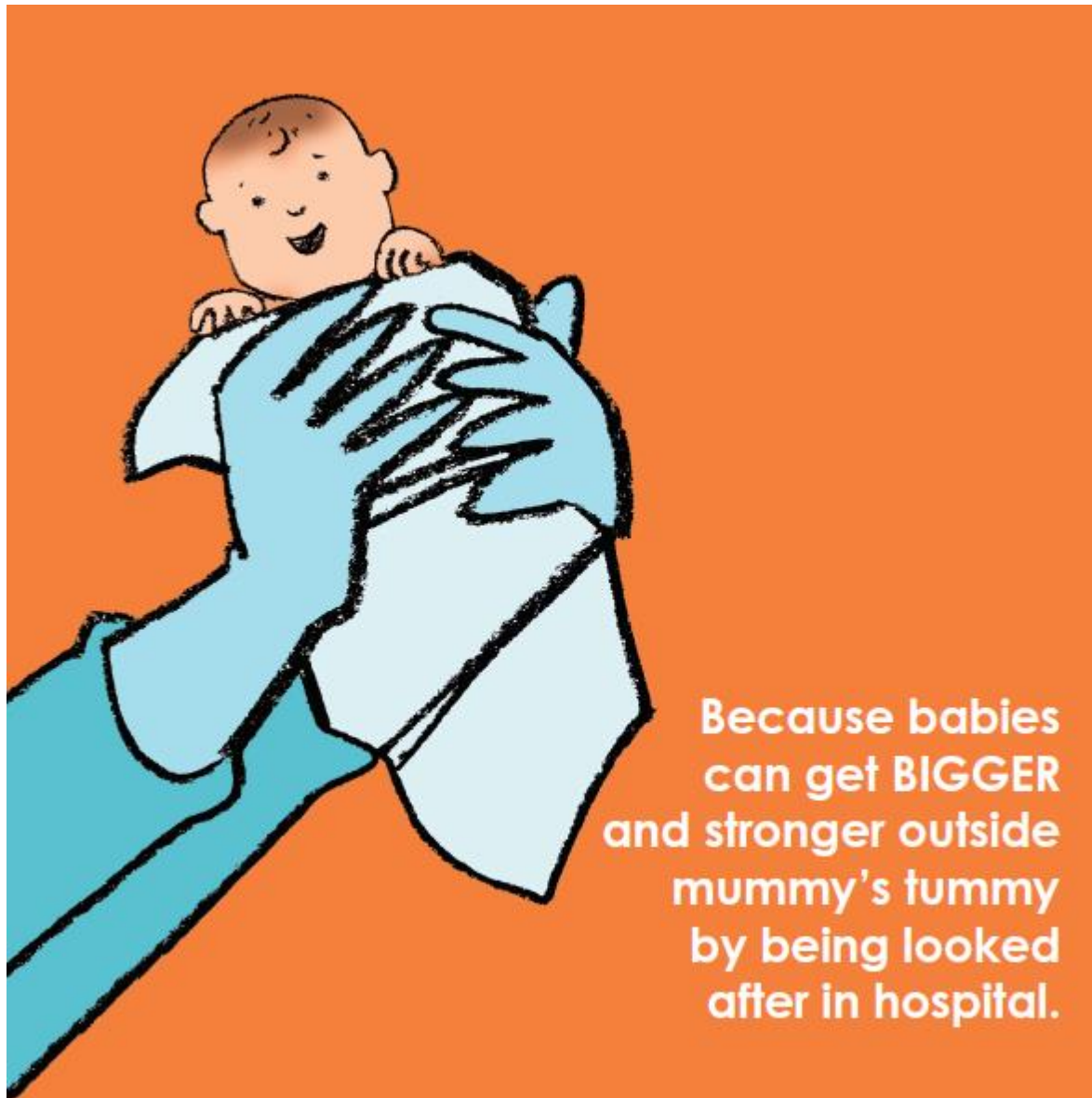
Baby's come early!



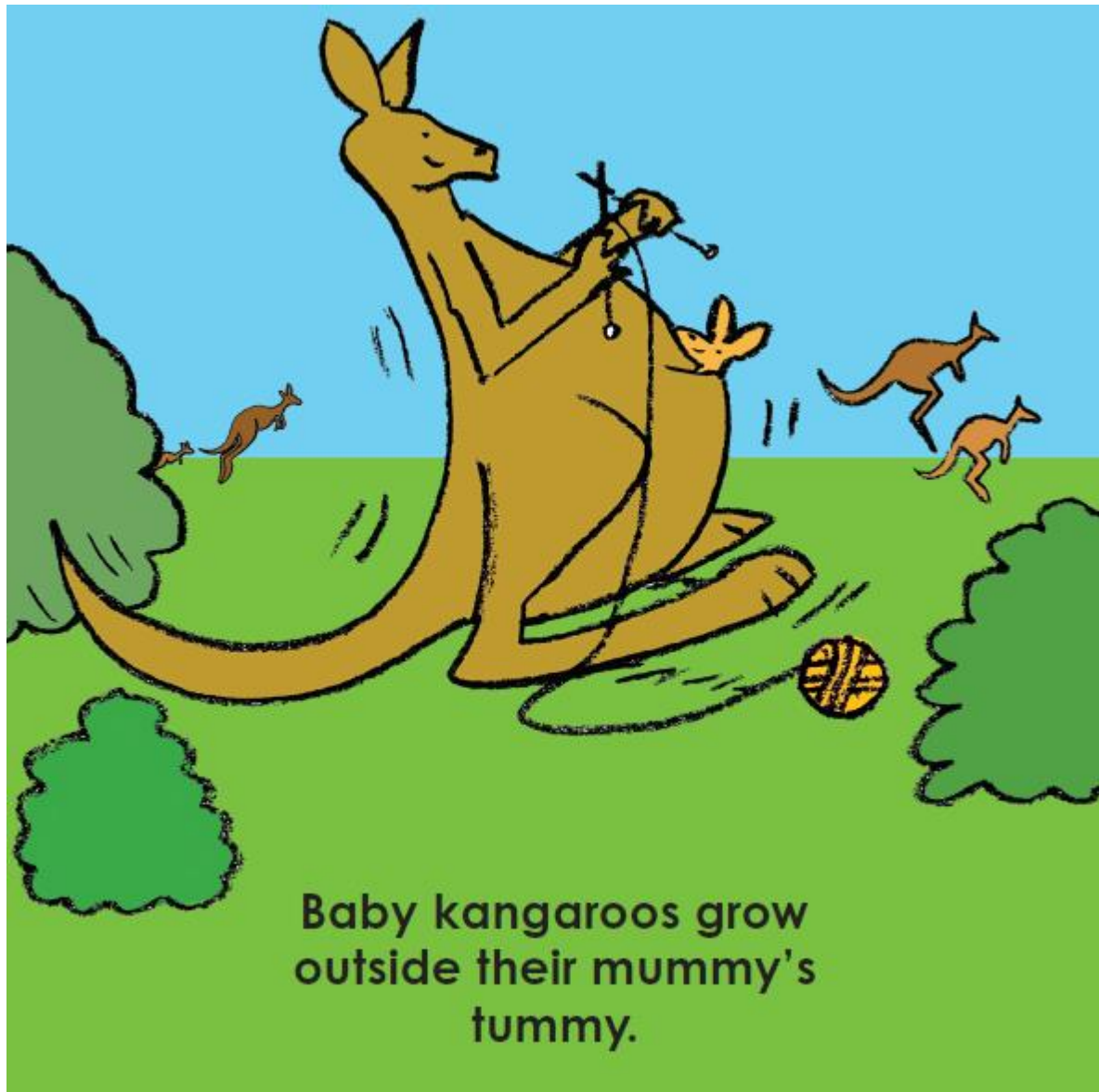


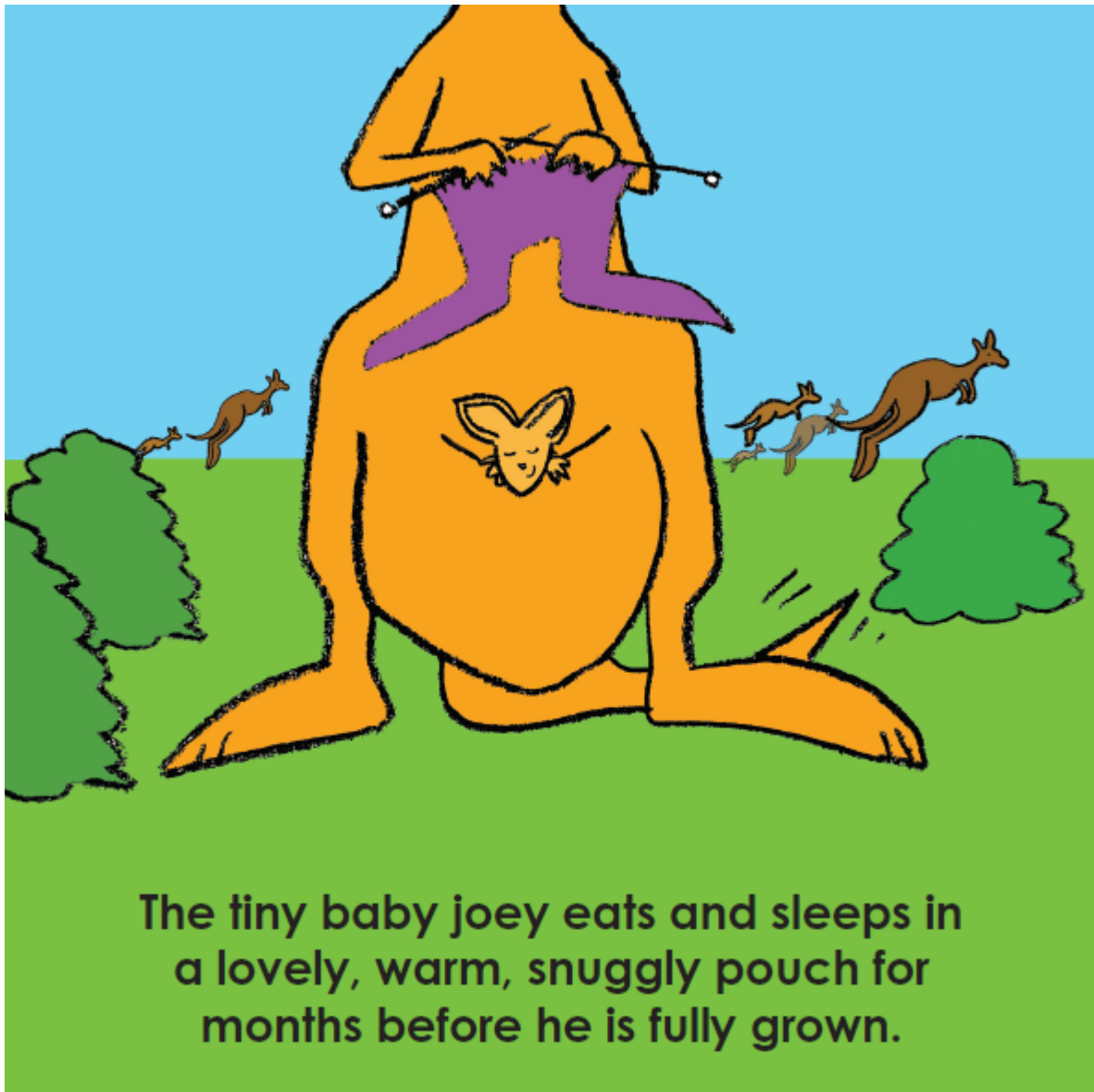


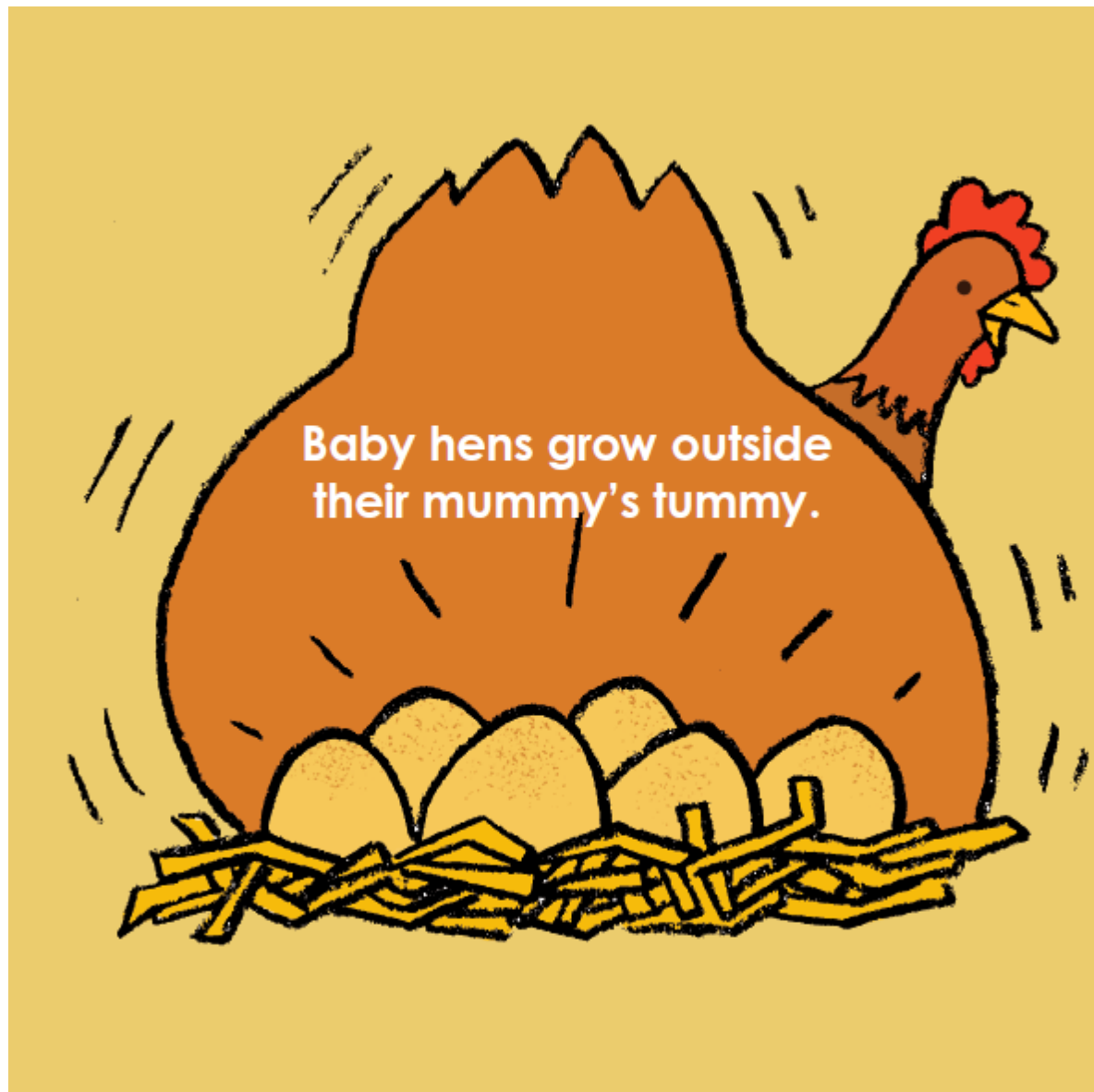


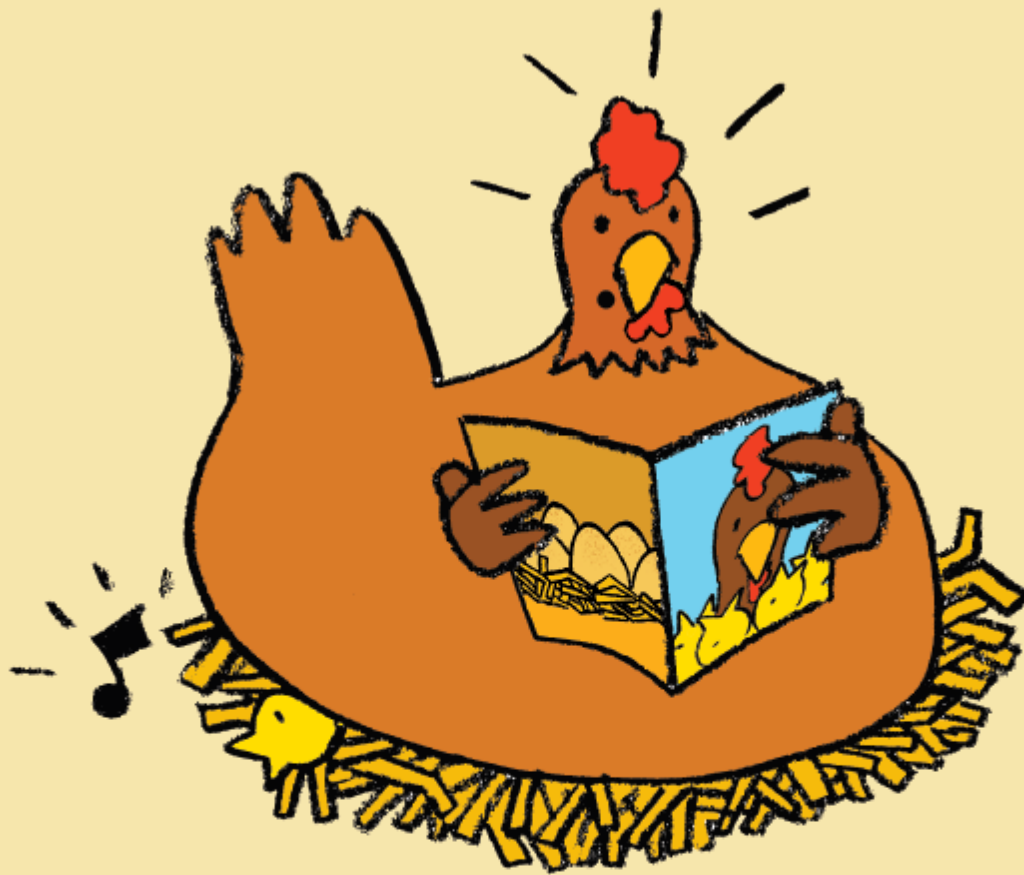








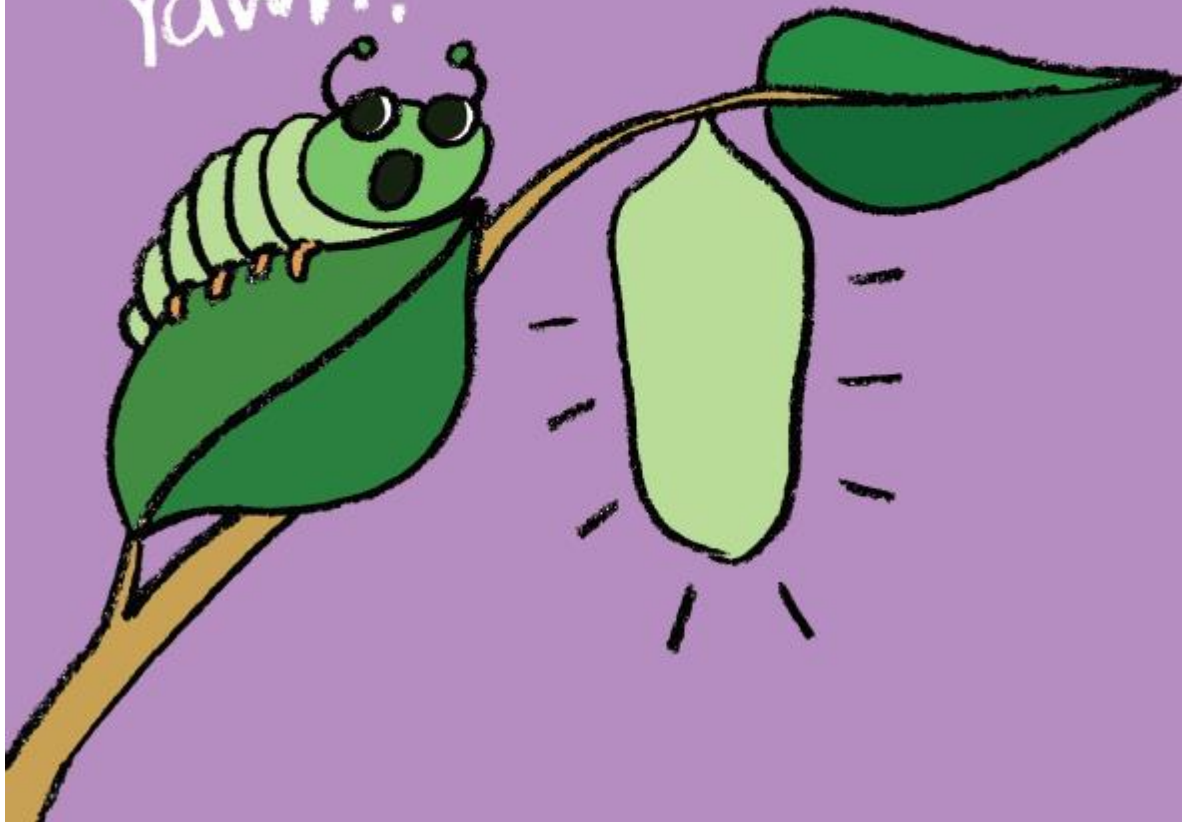




Their mummy sits on her eggs day and night.
Her baby grows fluffy and chirpy inside.

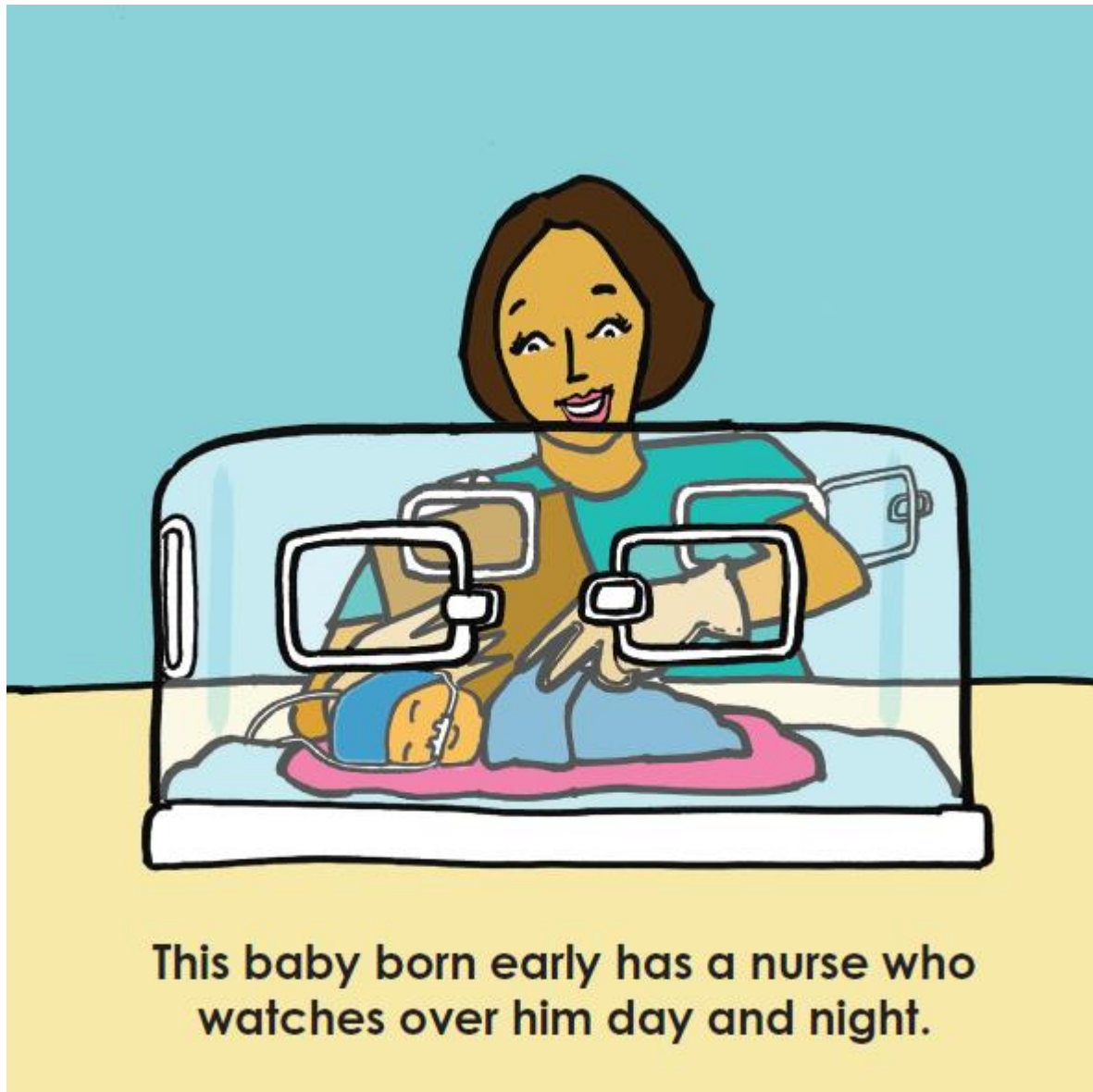
Baby caterpillars grow outside
their mummy's tummy.

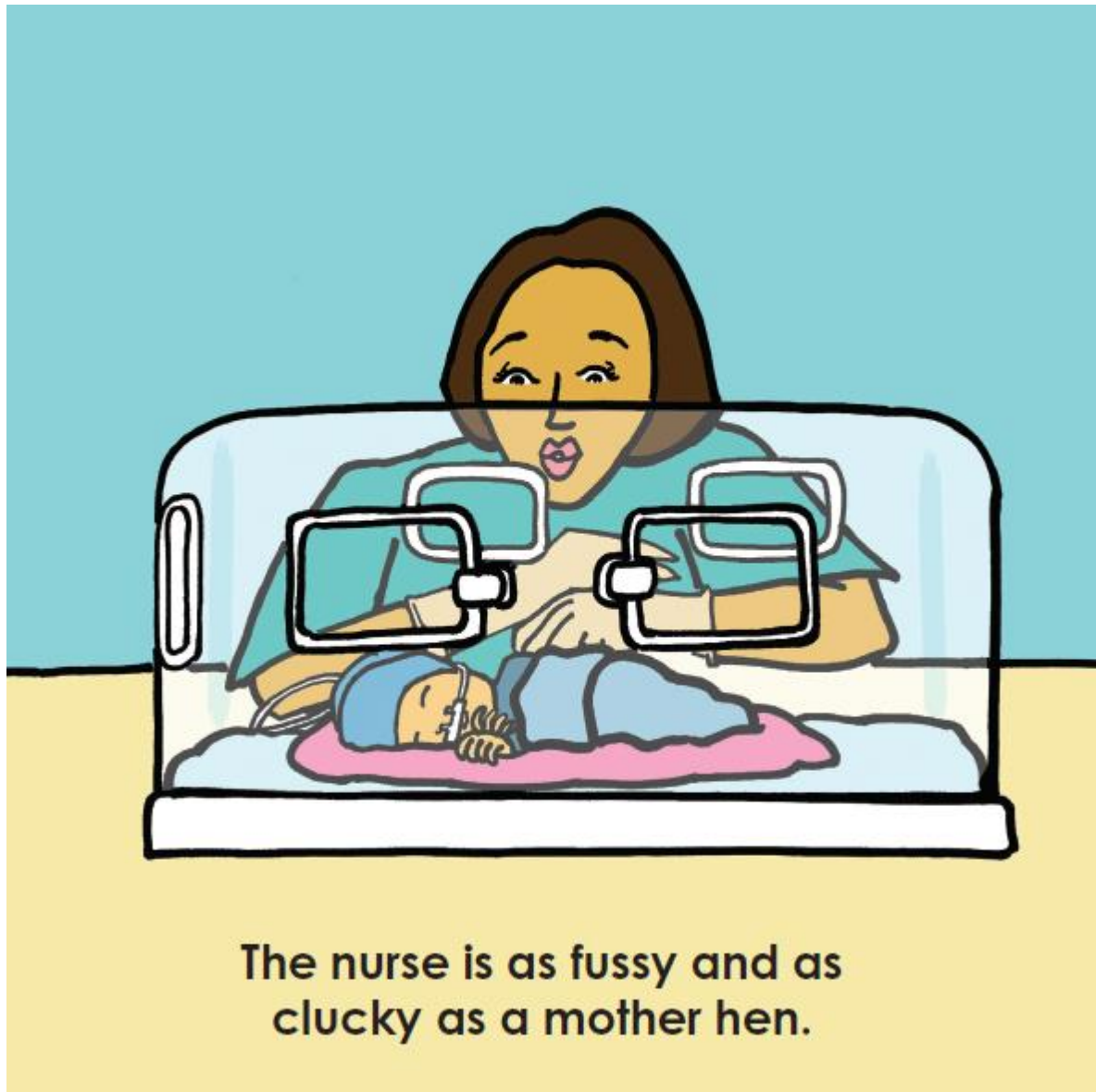
Yawn!





The little caterpillar sleeps in his cocoon
until he is born a beautiful butterfly.





This baby gets lovely cuddles from her parents
when they visit her in hospital.

Her skin feels warm against her daddy's chest.
It's as snuggly as when you get cuddled.





**And feels as warm and as safe as
a kangaroo's pouch.**



Some babies in hospital sleep
in a pretty cot that's as safe as
a caterpillar's cocoon.



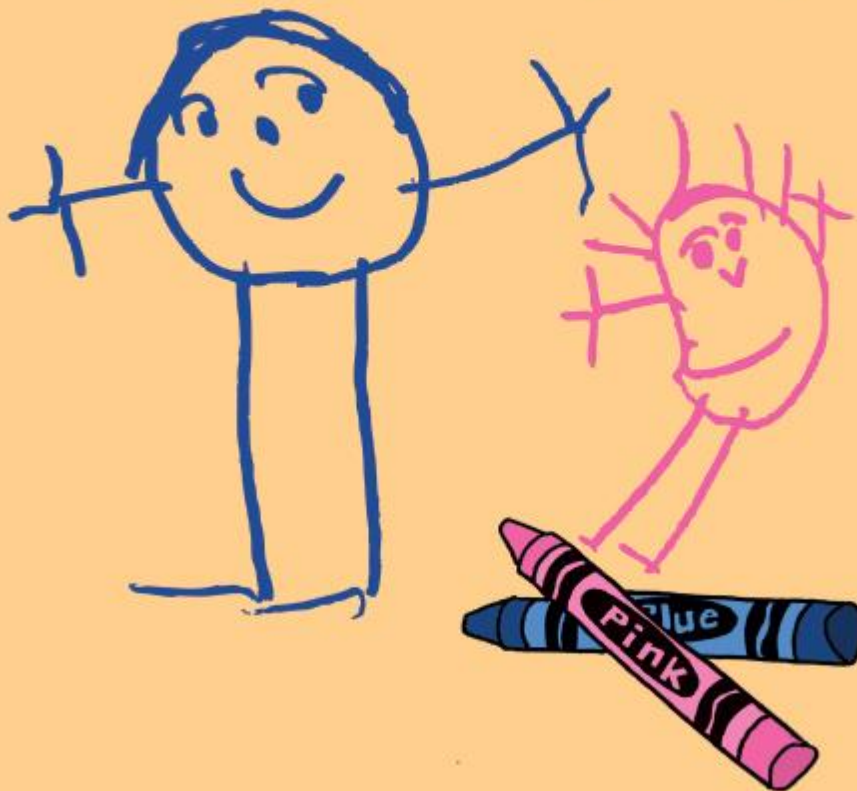
This baby sleeps here. He eats here.
He sees his family too.



**You'll be able to talk about their home
outside mummy's tummy.**

**It's as snuggly as a kangaroo's pouch.
As safe as being with a mother hen.
And as cosy as a caterpillar's cocoon.**

Draw a picture of you for mummy or
daddy to take to baby in hospital.



**Why not put a photo of your
baby brother or sister here?**





This book was created by the parents and staff at
Queen Charlotte's & Chelsea Hospital and with the help
and support of the Winnicott Foundation.

1.7 Support from the wider family and friends*

Parents with a premature or critically ill baby will need all possible help and support from the wider family and friends. But sometimes it can be challenging knowing how to show empathy and support in this unexpected situation. We prepared a few tips which may help the wider family.

Tips for the wider family and friends:

Let the parents know they are not alone in this journey, and offer your help. New parents can be reluctant to admit they need help, or sometimes they just don't know what help they need. The best thing you can do is to make a specific offer to help them.

If you are not sure of what things you can do to help, here are some ideas:



- If they have other children, pets or aging parents, offer to take care of them.
- Make them a home-cooked meal and take it to the hospital.
- Arrange to drop by and help with the housework.
- Offer to pick up their laundry from the hospital or from home and return it washed and folded.
- Do some grocery shopping for them.
- Drive them back and forth to the hospital.
- Respect the parents' wishes about how they want to mark the birth. Some may wish to celebrate. Others may want to wait until the baby is home. It is for the parents to decide and for you to support their wishes.
- Learn about prematurity, but don't feel the need to share what you're learning with the parents. Be careful about what resources you use, especially if you're researching online. Bliss, the preterm baby charity and the Best Beginnings: Small Wonders websites are good places to look. The Small Wonders DVD gives you a useful insight into what life on the neonatal unit is like.
- Accept if parents exclude you temporarily.
- If you are visiting the baby in the unit, respect the rules of the NICU, especially around hand hygiene. Don't visit if you're sick or if people close to you are sick. Respect the privacy of other parents and their babies.
- Offer to communicate with other family and friends so that the parents don't have to spend all their time updating everyone.
- Coordinate other offers of help so that the parents don't need to organise who does what.
- Keep offering help when the baby is home. The first few months can be isolating and difficult and parents can really use continued assistance.

- When a baby goes home, remember that preemies, especially during the winter months, are at risk for infections and sickness. Never visit the parents and baby at home if you're sick.

***Adapted from FICare Programme, Mount Sinai Hospital, Toronto, Canada**

1.8 Transfer back to local hospital

Most parents expect to have an uncomplicated pregnancy, deliver their baby and return home from the hospital where they booked after a few days. This is true for most parents but occasionally either the mother or the baby may need to be transferred to another hospital.

The North West London Perinatal Network (NWLNODN)

Early in your pregnancy you booked into a hospital for your maternity care. This is likely to be your local hospital which is also part of a network of 6 hospitals (NWLNODN) which offers care to babies after they are born. These hospitals work together to ensure that both mothers and their babies receive the care they need as close to home as possible.

All of these neonatal/special care units can provide emergency care for babies who are born prematurely or who are unexpectedly sick. Within the network hospitals offer different levels of care which is dependent on the severity of your babies condition. Tertiary (level 3) units care for the most premature and poorly babies, Local Neonatal unit (level 2) units care for babies when they are a little older and less sick, special care units (level1) when they are eldest or least sick.

The doctors' stabilised your baby in a hospital which was able to provide all the specialist care needed dependent on your baby's age and health at delivery. Your baby may stay in this hospital for days or weeks however when babies no longer require specialist care they will be transferred back to your local unit for continuing care before discharge.

Transfer to a hospital near to home

When your baby gets older and recovers and the requirement for specialist medical and nursing care is becoming less your baby will be able to move to another Network hospital near to home. Such transfer is a sign of the progress your baby has made and means you will be nearer to home at the stage when you are becoming increasingly involved in your baby's care. You will also become familiar with local services that will provide any continuing care after discharge home should your child require it.

We are aware it may also feel worrying and demanding to have to prepare for a move with your baby, to leave the unit you have come to know and to get to know a new hospital and staff. It is normal to feel anxious at the prospect of your baby moving to a new hospital. You may have questions you want to ask to help you understand the reasons for the move, and

what to expect at the new hospital. Some parents find it helpful for staff to arrange a visit to the local unit to meet well ahead of their baby being transferred.

The team at the new hospital will receive information on how your baby has been during his/her admission both verbally and in a written letter. Sometimes the transfer of your baby may occur very suddenly or may be cancelled at short notice. This is because the local unit may have an emergency admission or the transport team may be called to care for a sick baby.

Why can't my baby stay for the rest of his/ her care?

Some families express that they would like their baby to stay at the referral hospital for the rest of his / her hospital care rather than being transferred back to the local hospital. Unfortunately this is not possible because just as you and your baby needed specialist care there are other families who are waiting to be transferred for specialist care. You can be reassured that your baby will only be transferred to a unit providing the appropriate level of care for him / her once this level of specialist care is no longer required.

How will my baby be transferred?



Family Integrated Care in other hospitals

Integrated Family Delivered Care can continue to be helpful in your journey even if your baby is transferred back to local hospital. In the North West London Perinatal Network (NWLNODN), many units now have similar programmes and encourage parents to be involved in their babies care.

Share with your local team that you have been part of our “Integrated Family Delivered Care” and have completed a competencies documented in you [Steps to home booklet](#).

We understand that some of these practices may not yet standard practice in your local hospital but we hope that you will be able to continue to improve your skills enabling you to become more confident parent at discharge.

Key messages and reflection:

After this chapter you should be able to:

- know about coping strategies and tips in the neonatal unit
- understand how you can communicate better with our team and with your Baby
- use the 'Baby's come early' booklet to explain preterm birth and neonatal care to your other child or children
- learn how your wider family and friends can help you in this period.

Further learning in this topic

If you wish to know more:

- ask our neonatal team and psychology team at any time
- read the curriculum chapters especially **Chapter 1, 2, 5 and 12**
- ask for one-to-one support from one of our Integrated Family Delivered Care Project nurses
- use this app or your Parent Binder to record your notes and questions
- attend the weekly Parent Group meeting facilitated by our psychologist
- attend small group teaching in topic: **Managing anxiety and stress**
- ask about peer support by veteran parents

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Resources

Me and My Baby, FICare programme material, Mount Sinai Hospital, Toronto, Canada

A Guide for Parent and Families of NICU Babies, Sunnybrook Health Sciences Centers, Toronto, Canada

Bliss Family Handbook, BLISS, UK: Information and support for families of premature and sick babies (given out in your welcome pack: please ask the ward clerk if you have not received a copy)

Look at me – I'm talking to you: watching and understanding your premature baby. BLISS, UK.

Best Beginnings: Small Wonders films