



CPBF  FBPC

Canadian Premature Babies Foundation
Fondation pour Bébés Prématurés Canadiens

WELCOME TO THE CLUB

An introduction to the Neonatal Intensive Care Unit by parents for parents

A message for new NICU parents

We are all parents of NICU babies though our stories are all very different. Some of us were in the hospital for a long time, and some for a few weeks. Some of our children show no signs now of their prematurity or early struggles, and others have some challenges. Some of us endured losses and some had a quick and uncomplicated time with our babies in the NICU. We have all been forever changed by this experience, and we all love our children more than we ever could have imagined.

We filled this booklet with everything we would tell you if we were able to sit and talk with you. We did not include much clinical information about medical issues because we think those conversations are best had with your medical team. We encourage you to ask questions and be present for your baby or babies during your NICU stay. The medical team members do wonderful things, but you are the only people who can be parents.

While it's important to be aware of the risks and complications that could lie ahead, it's equally important to remember that it is also possible, even probable, that life a year from now will be joyful. We wish the best for you and your family.

10 questions for your NICU health care team



1. What can I do to take care of my baby?
2. Who are the other people in the NICU who will be taking care of my baby?
3. How can I contact the NICU? Who do I talk to if I have questions?
4. What are rounds and how can I participate in them?
5. How long might my baby be in the NICU?
6. What is that equipment in my baby's room, and can you explain what the different alarms mean?
7. What are some typical experiences that a baby like mine might have in the NICU?
8. What resources and support services are available for me and my family, both in the NICU and in the hospital?
9. Are there any limitations on when I can be with my baby in the NICU, or who can visit me and my baby while we are here?
10. How will I know when my baby is ready to be transferred to another hospital or discharged home?

“How did you do it?”

NICU Parents share stories and strategies

When you first arrive in the NICU it's so hard to imagine how the next few weeks, or months, might roll out. We asked some graduate families for their stories of how they coped with their stay, and what practical solutions they found. Thanks to all these parents for sharing!

Josee: The two things that helped me cope the best were keeping a journal, which I love to read once in a while, and making some good fellow mommy friends in the NICU.

Useful things others did for me? Sending prepared food was lovely. My mother also bought me some clothes as I had nothing there. We had many people who wanted to visit and found that overwhelming. My husband made a Facebook page to keep everyone updated without actually having to talk to anyone. I really wanted to just be isolated within my immediate family and the hospital, and my hospital friends. It was nice of everyone else to respect that need for privacy.

Sayid: We had such a hard time the first two weeks, and then things got calm, and then hard again before we went home. After we got home both my wife and I realized we were still struggling with our feelings, so we started to see a counselor. I never thought I would go see a counselor, but it was great for us both. The NICU is so hard on parents and there is no shame in asking for help. I wish we had asked for help sooner; it would have spared us many tears.

Heather: Some refer to it as a rollercoaster, but as an avid runner I like to compare our NICU journey to a marathon. Our son was born at 23 weeks+ 5 days and so spent many months in two different NICUs.

Like many other NICU moms I pumped around the clock (10 times a day) and commuted up to 1 hour per day to visit our son. To be as efficient as possible

I stuck to the same routine. When I wasn't pumping, I would participate in Rounds, assist the nurse with handling, do Kangaroo Care, read children's books to our son and absorb as much information as possible from other parents in the NICU.

By 8:00pm, when my husband would arrive at the NICU after work, I was usually mentally drained. I would brief my husband on our son's status over dinner and he would stay for a couple of hours while I headed home to pump and get meals organized for the next day. There was never a shortage of frozen meals in our freezer from neighbours and friends, but cooking was comforting for me, and made it easier to come home to an empty house, so I often looked forward to going home to cook a meal. When I was fully recovered from the C-Section I also added a run into the mix, mostly to clear my head after a stressful day.

I think most NICU parents look back on the experience and wonder how they managed. I think you just find a hidden strength that you never knew you had.

Dan: We lived far away from the hospital, and so would come down one day, stay over, go home the next day and sleep at home. Sometimes we felt bad about not being there all day, every day, but we needed to keep things stable for our son at home too. I think you find the way to do the best YOU can, and that's as much as you can do. Feeling guilty all the time will just burn you out. We also took days off when we needed to. When we got transferred things were easier, especially for my wife. Being closer to home made a big difference.

Lauren: We had our little guy at 25 weeks. I was in the hospital every day and night for the first two weeks. I made sure I was at rounds in the morning and met both the day and night nurse in person – I wanted to know who was taking care of him! The first two weeks were extremely stressful, emotional, and filled with ups and downs as I am sure everyone can relate to. During the third week of our journey my husband

pointed out that we had another three months to go and it was time to listen to everyone about BALANCE. So we made a compromise. I would take Sunday off for me to run errands, nap, just catch up on life as long as he went! We now each have a “day off” each week. We take care of all the meals and household chores for the other on their day off so they can focus on what they want to do with their day. This one day completely reenergizes me for the week ahead. I hope this helps others manage their journey.

Celeste: The biggest thing for me is that there is no one right way to get through this. Everyone is full of opinions about what you should do, but they don't know you or your situation. So you have to make up your own mind about what you and your own family need. If I wanted to be at the hospital, I was there. If I needed to be home, I went home. That changed when we started getting ready to take my baby home. I needed to be at the NICU all the time for feeding. I found that hard, but I got through it. I just kept telling myself it wouldn't be forever. Now it all seems like a dream.

Keisha: I celebrated EVERY SINGLE THING my son did. I'm not really exaggerating! His first poop, his first bath, his first everything! Our nurses helped by making certificates and doing footprints and name cards for him. I felt so sad about missing out on all the fun baby stuff like baby showers, and this was a way

of getting back that baby joy. Now he is 5 and loves to see his huge scrapbook full of memories.

Sara: One thing I didn't know up front that I wish I had known, is that whatever schedule you come up with really only works for a week or two. Then your baby will change and learn something new, or you'll be able to change your pumping schedule, and so everything else will change! So at first you want to be there all the time because you're feeling scared. Then you work out a way of balancing your life better. But then you get transferred and change everything again! And then your baby is getting ready for home and it all changes again! So I would say don't feel like you have to plan the next three months. Just come up with a plan week by week and change as you go. Living with uncertainty is hard but I think it is a normal part of the NICU experience.”

Some common themes from these stories?

1. There is not one right way to do things. Find what works for you.
2. Ask for and accept support.
3. Take care of yourself.
4. Draw upon past coping strategies.

Feeding your baby

The evidence from research is very clear: breastmilk is best for babies! This is true for all babies but particularly for premature or sick babies.

In the NICU, breastmilk represents more than just food. It is also medicine that protects babies from infection, reduces the severity of illness if they should become sick, and promotes healing, growth and development. Most premature babies, especially ones born before 35 weeks, aren't ready to breastfeed at birth. They will be fed through a tube until they learn how to eat by mouth. A wonderful gift that you can give your premature baby is your breastmilk, and hopefully you can start to give that gift right away.

In some hospitals, you will be encouraged to use your hands to express milk from your breasts right after your baby is born. It is normal to only get a few drops when you start, but those few drops will do wonders for your baby! Ask your team about hand expressing, or for help in starting to make milk for your baby. You may also want to ask about the availability of donor breastmilk; commonly it takes a few days for your own supply to kick in.

In order to build your milk supply and get enough breastmilk for your baby's feeds, it is best to use a hospital grade electric pump. Ask your health care providers about how to get a pump and the related equipment. They will also show you how to clean your equipment and kits. If you pump for 8-10 times a day for the first two weeks, you are giving yourself the best chance of building a great milk supply. Over time, many women pump quite frequently during the day, and then take a four to five hour sleep stretch at night, waking only once to pump.

If you are finding it hard to build your supply, are experiencing any discomfort with pumping, or have any questions about breastmilk or feeding your baby, ask to speak with a lactation consultant. Many hospitals have lactation consultants in the NICU or can arrange a meeting for you.

Sometimes women have medical issues or other reasons why they cannot make breastmilk, which can cause feelings of stress and guilt. If you find yourselves in this position, try to talk to yourself the way you would talk to a friend in the same situation. Show yourself kindness, and realize that in the end, what is best for you is best for the baby.

Because NICU babies need a bit of help with growth, their feeds are often fortified. Some hospitals use a fortifier made from human milk, and some use a fortifier made from cow milk. NICU dieticians are a treasure trove of information about nutrition, and can answer questions about your baby's feeds and growth.

When your baby is ready to start breastfeeding or bottle-feeding, please know that it often takes a while to get the hang of it. Breastfeeding is natural but doesn't always come naturally! Both you and your baby are learning. This is not just true of breastfeeding; bottle-feeding is also a learned skill, and both babies and parents benefit from taking time to learn and not rushing.

It is hard for NICU parents not to worry about how our babies are feeding and growing, but it is also important to focus on enjoying the experience of feeding your baby. If we remember to slow down and let our babies learn these new skills without pressure, we are helping them understand how enjoyable food and eating can be, and we are bonding with them as well.

The Magic of Touch

Everything about you is good medicine for your baby. The sound of your voice, the taste of a mother's milk, the knowledge you have of your baby ... and the magic of your touch! There are many ways your touch can help your baby. You can hand-hug, do kangaroo care, and when your baby is bigger and ready for it, you can do baby massage.

Kangaroo care, also known as skin-to-skin care, is when a baby is held by a parent on her or his bare chest. Scientists have all kinds of great words to describe what kangaroo care does for a baby (and a parent), but we will use a non-medical term. It's magic!

When babies are held, they self-regulate better, grow better, sleep better, and it helps their brains develop. When parents hold babies, their stress levels go down, they feel more confident as parents, and moms make more milk! And these are just a few of the proven benefits.

You may feel nervous the first time you hold your baby, especially if he or she is very small. It gets easier. Parents say those hours spent holding their babies are the most precious memories of their time in the NICU.

If your baby is not having the kind of day that allows for kangaroo care, or if your time is limited, there are other kinds of touch that are helpful for both you and your baby.

Hand-hugging is when parents, with clean hands, place one hand on a baby's head and cup the other around the baby's bottom. This is especially

appropriate for very new or fragile babies who may not be ready to be transferred to a parent's chest. When your baby is awake or upset, talk or sing quietly to him or her while hand-hugging; she or he will hear your voice and will also feel your voice through your hands.

Modified kangaroo care or encircled holding is when the top of the incubator is removed, and the parent leans over the baby while the baby is still in the incubator. This is a wonderful way to connect with your baby. It doesn't necessarily last as long as a standard kangaroo care session, but parents report some of the same positive effects, especially with respect to milk production.

Tips for touch

- Always visit the bathroom and have something to eat and drink before a kangaroo care session.
- Moms, think about your pumping schedule and when might be the best time to pump. You may find that you produce more milk right after a long kangaroo care session.
- Most hospitals are scent-free; this is especially important for kangaroo care. Babies prefer your natural smell over the smell of perfume, skin cream, or cologne.
- Check in with your baby's nurse or with the team at rounds about what kind of touch is best for your baby that day, and what time will work best. You can also call in to discuss timing with your baby's nurse.

Keeping your baby safe in the NICU

You're not just the parent to your child — you're also chief safety officer! Parents and families play an essential safety role in the NICU. Here's what you can do to promote safety and protect your baby.

Clean your hands and ask those around you to do the same

Use soap and water after using the bathroom or any time you have visible soil (such as milk, stool or mucous) on your hands. You can use alcohol hand sanitizer when hands are not visibly soiled. Use sanitizer before and after touching your baby. Become aware of what your hands are doing and what they're touching. Remember that electronic items like phones or laptops can be a pathway for germs; keep them clean!

Take off hand and arm jewelry and artificial nails

Germs can hide under rings, watches, bracelets and artificial nails. That is why many hospitals ask you to take off hand and arm jewelry and to remove artificial nails. If you have any questions about safety and hand hygiene, ask a staff nurse.

Stay home if you're sick

We want you to be with your baby, but if you're sick it's better to stay home. For one, you don't want to pass germs to your baby or to others in the NICU. For another, you need to be well to take care of your baby. If you are wondering if you should come in or stay home, err on the side of caution and call the NICU to

talk to a nurse for advice. Ask your family and friends to do the same. Even if they come to the visiting areas of the hospital, if they're ill they're spreading germs.

Let the NICU team support you

Sometimes it's hard to get family and friends to understand how important safety rules are. If you're running into resistance, let your NICU team help. A staff member can help educate your nearest and dearest about the hospital's policies, leaving you to focus on your baby or babies.

Ask about medication and medical apparatus

Feel free to ask questions about any medication that the team members give your baby or any medical apparatus (like ventilators) that they use, so that you have a clear understanding of what is being used, why it is being used and how it functions. Some parents take notes or add medication and equipment info into their daily journal.

And you can support the medical team. Talk to the team about safety; share your thoughts, concerns and questions.

The team needs to hear from you when they're doing something right and when they could be doing something better.

You should feel safe speaking up. By sharing your thoughts, you help make the NICU better for everyone. If you have any questions or concerns you can speak to a staff member. You are your baby's voice, and you will feel better after sharing your concerns and questions with your baby's team.

Focus on Fathers

Thank you, Andrew, for sharing your story and your advice for other NICU Fathers.

When my wife told me that we were pregnant, I never could have imagined how the next 12 months would play out. I had just started my new job in which I work remotely from home, eliminating my commute and allowing me more time at home with our child once born. Things were shaping up quite nicely.

But then my wife's water broke in the middle of the night. We drove to the hospital where she was admitted into the High Risk Obstetrics Ward; a week later, our daughter was born at 25 weeks gestation.

Everything has turned out well for us in the end. Our stay in the NICU was a very positive thing, but lasted several months, which can be taxing on anyone. If I can share any advice with other NICU fathers, it would be:

Keep some balance

In total, we were just shy of 4 months in the hospital. Between this and work (as most of us dads continue working during this), it's easy to get emotionally and mentally drained – no one can keep their spirits up that long if all they know is work and a hospital room.

I kept some balance by trying to get to the gym most days. This was a good tool for me to burn off the stress of work and/or the hospital. For you, whether it's the gym, music or something else, try to keep up something that will help keep a fresh mind.

Be at the hospital every day that you can

Being at the hospital daily not only allows you to see more of your child, it keeps your wife from feeling isolated in the NICU experience. Additionally, having face-to-face time with the medical staff allows you to know your baby's caregivers and ask questions. You also get to participate in the care for your preemie,

whether that's changing diapers, taking his/her temperature, or Kangaroo Care.

I realize this is not possible for all fathers. We were fortunate in that we were close, I could work remotely in the hospital, and we don't have any other children to take care of. However, I felt better the days I was able to hold my daughter and talk to her nurse; the days I was at a client site I was less at ease.

Don't feel odd being the only guy

The NICU can feel like a pretty female-centered environment. For example, it can sometimes feel odd being the only male in the Family Lounge during an information session – there might be 2 women presenting, 6 mothers, 2 grandmothers, and you're the only man. However, once you take part in the session, you realize that discomfort is only in your head, and that the NICU community is focused on getting babies healthy, and staying healthy once they're home. Also, babies need their dads. Babies love hearing the sounds of a father's voice and they love being held by their fathers. By being present, by supporting your partner, and by being there for your baby, you are being a great dad, even if it doesn't feel like what you expected.

Anticipate and plan for the discharge date

One of the challenges for NICU parents is not knowing the discharge date. When our daughter arrived in the NICU, we were told she would stay up to her due date, and likely beyond – it all depended on her progress. So I had trouble planning on when to take time off work – if I asked for the week of my daughter's due date, what if she wasn't discharged? Would I have to keep moving my vacation back a week at a time each week?

By the time she was discharged, I was in the midst of wrapping up a project at work, and wanted to close it out (it was so close to being finished, I felt it was easier to do myself rather than try to hand it off). We stayed overnight at the hospital for 1-2 weeks before

our daughter was discharged (where I didn't sleep very well); when our daughter came home, like most babies, she would cry at night (and I wouldn't sleep very well).

I ended up working for 5 weeks after our daughter came home before I took a week off – I was completely mentally drained after 7 weeks of not sleeping enough and having the stress of work to deal with. If I could have done this over again, I would have tried to transfer the project to a colleague a couple weeks before our daughter's due date, and taken on a short term project and/or provided support on the project rather than be the lead.

Everyone's work situation is different, but I felt of everything in our NICU experience, this was the piece I handled the worst, and would advise anyone else from doing this if they can avoid it.

Overall, our experience in the hospital was a positive one – we didn't expect a positive experience when my wife's water broke. In addition to all the other firsts we experienced in the hospital, we've now experienced first birthdays and my first Father's Day at home, and I couldn't be happier.



How are YOU doing?

Spending even a short time in the NICU can be stressful. While you are understandably spending a lot of time caring for your baby, you also need to care for yourself. Babies need healthy, confident families to take them home. Emotions in the NICU are different for each person; you may find it is like being on a roller coaster, up one minute and down the next. The uncertainty is not easy to deal with, along with all your “outside the NICU” life commitments. Health care workers in the NICU, your family and your friends can help with:

- **Emotional support:** finding professional counselling or just a shoulder to lean on
- **Financial guidance:** from learning about social assistance to finding out about community and/or hospital resources

- **Knowledge:** helping you get your questions answered by the best person
- **Practical support:** family and friends can make you meals, help you with household tasks, communicate on your behalf with other family and friends, or drive you to the hospital.

If you find yourself struggling with your feelings, please know that you are not alone, and that there is help for you. Most hospitals have social workers who can refer you to services, or you can talk to your family doctor. It is very common for NICU parents (both mothers and fathers) to feel depressed, sad or anxious, and the best thing to do is ask for support. You may also find an online support group helpful; the Canadian Premature Babies Foundation has a national group (www.cpb-fbpc.org) or you can ask your hospital’s social worker if there is a local group you can join.



Coming Home from the Hospital

All parents want to know when their babies can go home. Some babies go home a few weeks after their due date, some go home around their due date, and some go home a bit before. In some parts of the country, babies are transferred from their birth hospital to a community hospital before going home. Generally speaking the earlier the baby, the longer the hospital stay. Babies are ready to go home when their breathing is stable, they are feeding by breast or bottle well, they are gaining weight reliably, and they have no pressing clinical issues that need monitoring at a hospital.

Some units have a discharge planner or staff member who will meet with you before your baby is ready to go home to discuss with you the steps that are involved. The days before discharge can be emotionally challenging. One moment you are excited, the next you are worried. You can't wait to be back home, but you may be nervous about losing the support you've had in the hospital. If you do feel this way, you're not alone; many parents find discharge day to be bittersweet (though mostly sweet).

Many NICU parents say they feel bad because they did not get a chance to take prenatal classes before their baby's birth – but in a way, the NICU can be like one big prenatal class! Every day you'll learn something new about your baby. There are some things you want to make sure you know about before you go home. Ask your medical team about safe sleep practices, car seat safety, how to do tummy time with your baby, and what kinds of appointments your baby will be going to after you go home. Some babies will be seen by a paediatrician, and others (especially those born very early) may also go to a Neonatal Follow Up Clinic for regular visits. Make sure you know who to call if you have questions after you leave, whether it is your family doctor, your baby's paediatrician, or a specialist at the NICU or Follow Up Clinic.

One concern many parents share is that their friends and family do not understand that their NICU baby, even after going home, may still need to be treated differently than a baby born full-term without medical complications. That's why we have prepared a letter for you that you can share with friends and family before discharge. Please feel free to adapt the following text for your own use.

Dear Family & Friends,

We are so excited to announce that soon we will be bringing our preemie home, and we know you share in our excitement.

Though we are leaving the NICU, we will be bringing home many of the practices and habits that we learned there. Our medical team has told us that we must be very careful in the weeks and months ahead, since we want to protect our child's health and development. Illnesses that are minor irritants for term children can send preemies back to the hospital, which is something we all want to avoid. One example would be RSV, also known as Respiratory Syncytial Virus. This is a very common virus that turns into a bad cold for you or I, but becomes a life-threatening illness for a preemie.

The way we care for our child may seem different than what you are used to or what you may have done with your children, but our actions are based on medical advice that is specific to our child and family. We appreciate your support, acceptance and understanding.

We will be following our doctor's advice about limiting visitors over the next few months. Big events with many people are not suitable for a vulnerable preemie, so it is much easier for us to visit in small groups or to host a single visitor.

If we are able to have you over, please ensure the following:

1. Please be completely healthy. If you have a cold (even a minor one) or think you might be getting ill, please postpone the visit to a later date. If you are not sure, please ask us, and please don't be offended if we suggest postponement.
2. Please wash your hands upon entering our home, and please be thoughtful about hand hygiene during your visit.
3. Please do not smoke before or during a visit with us.
4. We will be following our doctor's recommendations regarding vaccinating and medicating our child and our family, and we would appreciate it if you would support us in this. We also encourage you to make sure your immunizations (including the flu shot) are up-to-date.
5. We are following very specific guidelines related to feeding our baby, and also following standard safe sleep guidelines. If you are helping us care for our baby, please follow these guidelines as well.
6. We greatly appreciate your understanding and your help. We are also grateful for the support you showed us during our NICU stay, and we look forward to seeing you soon.

NICU World and Home World: What are the differences?

When parents first enter into the NICU for the first time, most of us can't imagine that we'll ever get used to it. It seems like such a strange environment ... it's "NICU World", full of beeps, machines, numbers, and lots of people. Not quite like an amusement park, despite the frequent references to rollercoasters.

With time, though, it does become familiar ... and then by that point we are either transferred to another hospital or discharged home. Just as we've learned all the ways of this new world, we're sent to another. And our world at home looks quite a bit different from the NICU.

So are all the lessons we learn in this strange NICU World wasted? What can we leave behind? What can we take with us?

With the help of some graduate NICU parents who have spent time in both NICU World and Home World, we've come up with some helpful lists.

We will leave behind in NICU World ...

- reliance on monitors and other things that beep. We probably won't need these in Home World. We'll get by just fine with our own knowledge of our baby and our 5 senses. We'll know when something's wrong and we won't hesitate to ask for help. If our baby does go home on oxygen with a monitor, we will remember that it's a useful tool, but not more important than we are!
- hospital schedules. In Home World there aren't rounds or shift changes or external schedules . We will do what's best for our baby and family. We'll recognize that as our baby grows his or her rhythms will change too.

- daily weights. We'll have to give up our fascination with those numbers! Instead, we'll pay attention to our baby's cues and to numbers of wet and soiled diapers.

We'll take with us ...

- the knowledge that we are the best medicine for our baby. Our touch, our smell, the taste of our milk, our love, our patience, the sound of our voice, our presence. These are what matter most to our children.
- good hand hygiene and infection control habits. We may find that others in Home World think we're being too uptight. WRONG! For the first year after our baby comes home, we'll follow the same hand hygiene rules as we did in the hospital, and we'll tell our friends and family not to visit if they're sick. After that, if all goes well, we'll relax ... a little.
- an appreciation of the day-to-day joy of being with our children. Our babies are going to continue to move forward to the beat of their own drum. That was hard for us when in the NICU, and it will continue to be hard, especially when we are surrounded by families who are having different experiences. When it gets really hard, we will hug our babies and remember just how far they've come. We will celebrate every milestone and not take anything for granted.
- the willingness to ask questions and work with a team. Just as our questions, insights, gut feelings and comments were vital to the wellbeing of our baby in the NICU, they still are once we've gone home. We've learned that it's important to speak up and we won't forget that lesson.
- the friendships we've made with other NICU families and staff. They more than anyone else understand what it's like. We will treasure these friendships for the rest of our lives.



About the Canadian Premature Babies Foundation

The Canadian Premature Babies Foundation (CPBF-FBPC) created this booklet to support NICU families. CPBF-FBPC was founded in 2012 by Katharina Staub, the mother of prematurely-born twins. Our team now consists of parents and clinicians working together to improve experiences and outcomes for children born preterm. We have established a national peer support group for NICU parents, developed and delivered peer training modules, created online resources for families and clinicians, distributed publications for parents on common winter illnesses, coordinated events across Canada for World Prematurity Day, initiated a bursary program for NICU graduates, and participated in innumerable research projects to improve outcomes for NICU babies and their families. Visit our website at www.cpbf-fbpc.org for more information.

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