Helping siblings cope with the NICU (Neonatal Intensive Care Unit)

Information for patients and families
Read this booklet for:

- General information on siblings visiting the Neonatal Intensive Care Unit (NICU)
- Tips on how to help your children, based on their age group
- Ideas for keeping siblings busy
- Supports for parents


**Introduction**

Having a baby in intensive care is stressful for all parents. It can also be stressful for other children at home.

In this book you will find ideas on how to help your other children cope while their brother or sister is in the hospital.

Parents are the main support for siblings, but the NICU team is here to help make it easier.

Please speak with your social worker if you would like more information or ideas for your children.

**Can siblings visit the NICU?**

We encourage all siblings to visit the NICU. It helps them understand what is happening, and it will help them cope better with this experience.

Talk through some of the common questions kids may ask before they visit.

**What is a NICU?**

Explain that this is a Neonatal Intensive Care Unit. Explain that babies who are born early, or need medication, have to stay in the hospital before they can come home. Tell them about what it looks like, and how they have to wash their hands when they come to visit.
What are all the machines?

The machines can look frightening, so it helps to explain what they do. Explain what each machine does (for example, helps the baby to breathe, monitors the baby’s heart rate). The nurse can help you do this. Also explain that sometimes they make sounds and beeps so the nurses can check on the baby.

What will the baby look like?

It might help to show siblings a picture of baby in their crib or isolette.

Older children might like watching a video tour of a NICU. You can find a video on YouTube called ‘NICU Tour for Siblings’, produced by Hand to Hold.

Is the baby in pain?

You can explain that there is medicine to keep the baby comfortable and out of pain.

Can I hold the baby?

Most siblings will be allowed to touch and hold the baby with their parents’ help. The nurse can tell you if the baby can be held by them and will help you on the day.

Planning for your visit

- All siblings may visit. Children under the age of 12 must be accompanied by an adult.
  - They must be vaccinated.
  - They must not be sick.
  - They must follow hand washing guidelines on entry.
• Plan to keep visit lengths short for younger siblings. Children often get bored in the NICU after a short time.

• For children under the age of four, it may be better to come when you have another adult available to play with them if you’re tending to the baby’s needs.

• Bring some toys for sibling to play with by the baby’s bedside.

**How will my other children react to this situation?**

How your other children react to the baby’s arrival will depend on a number of things. This includes their age, their developmental stage, how they usually react to stressful situations, and the amount of support around them.

**Babies and Toddlers**

**How they may act and think**

While they can’t understand what has happened, they do pick up on stress. You might find they are more clingy when you are around, or distressed at times.

**How do I help them?**

• Keep their usual routines. Don’t introduce any other major changes if possible at this time (for example, toileting).

• Hold and cuddle them as much as possible, and keep voices calm when near them.

• Offer comfort item such as pacifiers, blankets and soft toys.
Preschoolers

How they may act and think

Like younger children, they will be aware that something is going on. They may react to this by looking for your attention, having more tantrums, or regressing in tasks they were doing independently (for example, toileting or feeding).

How do I help them?

- They need to know in very simple language what is happening. They may ask the same questions a lot. Calmly repeat the answer.
- Using books or coloring books may help (please see the resources section at the end or speak to the social worker for more ideas)

4 to 6 years

How they may act and think

This is the age of ‘magical thinking’. They may feel that they caused this somehow (for example, from not wanting the baby to be born, wanting you to themselves, or other thoughts).

They may worry about what is wrong with the baby. They may also worry about other loved ones getting sick.

Remember they don’t understand why you might be sad or even angry at times. They might think they are causing your stress.
How do I help them?

- Explain 3 important things:
  - No one *caused* this
  - They cannot *catch* what the baby has
  - Who will *care* for them while the baby is in the hospital
- Encourage play, including medical play with dolls. They may act out what they see or believe. Use this to start conversations on what’s happening.
- If you are sad or upset, explain why. Explain that it’s not because of them.

6 to 12 years

How they may act and think

They will have the same concerns as younger children, but at this age they also have a deeper understanding of illness. They may worry more about the baby and what will happen in the future.

Older children will need to talk more about what is happening to their brother or sister, and what it means to them.

How do I help them?

- Answer their questions as simply as possible. Be honest. It’s okay to say you don’t know everything.
- Tell their teachers what is going on for more support.
- Encourage them to read to the baby or create artwork for the bedside.
- Set aside time with them alone and ensure it’s a calm and unrushed atmosphere.
- They need a lot of reassurance and support. Ensure this includes lots of hugs and affection.
Teenagers

How they may act and think

Teens tend to seek support from friends and peers more than adults. While they might not talk with you, they do worry about the baby, and the future.

How do I help them?

• While they may not seek conversation, it’s important to keep them updated around the baby’s progress.

• Offer them visits to the baby. Try and involve them in setting up for home and asking their opinions.

• Accept that they may respond negatively and avoid family time. Try not to allow this to start an argument.

• Accept that they may need time alone.

• Give them information around any peer support available and online resources about prematurity or medical conditions. See the resources list below.

• Tell their teachers what is going on. Stay in contact.
Activity ideas for siblings

- Decorate a picture of themselves to put near the baby.
- Decorate the baby’s name for the crib or isolette.
- Celebrate all milestones of the baby with their siblings (for example, first hold, feed, move to crib).
- Read their favourite book from childhood to the baby.
- Colouring books/stories about the NICU.
- Make a memory book or a book about their family for the baby.
- Medical play with a doctor kit and a doll.

Support for parents

Extension of childcare subsidy: If your other children receive a childcare subsidy, it is sometimes possible to get an extension during the NICU stay. Ask your medical team for a letter of support.

Gerrard Resource Centre: This center has some low cost emergency day care available. Call: 416-972-1319

NICU Family Support Program: There are a number of volunteers that help in the NICU. Their main role is to cuddle babies. However if they are available, they can play with your other children while you care for your baby.

Social Work: Social workers are available in the NICU to help you and your family during this stressful time. Ask a member of your healthcare team if you would like to speak to a social worker.
NICU and sibling resources

Canadian Premature Babies Foundation: www.cpbf-fbpc.org

Extend-A-Family: runs a number of support groups for siblings of children with special needs
http://extendafamily.ca/our-services/family-support-groups

Hand to Hold: http://handtohold.org/support/sibling-support

Parentbooks: a parenting bookstore located downtown. They have a suggested list of books for parents of premature babies, including some books for siblings. www.parentbooks.ca/Premature_Babies.html

The Sibling Support Project: an American based foundation which offers online support groups for siblings including teenage siblings of children with different medical and health needs. www.siblingsupport.org
Unity Health Toronto cares about your health. For health information you can trust, visit us online at unityhealth.to/learn or visit the Patient and Family Learning Centre at St. Michael’s Hospital.

This information does not replace the advice you receive from your health care provider. If you have questions, ask your health care team.