

# When your baby has a serious health condition

It can be very upsetting when the doctor tells you that your baby has a serious health condition, that she needs surgery or that her health has gotten worse. Often this news comes as a shock. You may be worried about what this means for your baby's future.

You may be overwhelmed when you first get the news about your baby's condition. Talk with the NICU staff and your family. Ask if the NICU has a social worker, counselor or chaplain who you can talk to. Write down a list of questions for your baby's health care team.

Have a family member or friend with you when you talk to your baby's doctor. This person can help you remember important information and give you support. Write down what the doctor is saying. You may need to talk to your baby's doctor a few times to ask all your questions. And, don't be afraid to request a meeting with the doctor. If you're not sure what to ask, talk to the NICU staff. The staff are there to support you during this hard time.

## Here are some questions you can ask your baby's medical team:

- Is this a short-term or long-term condition?
- How serious is the condition?
- What are the treatment options?
- Will my baby need to be treated by other doctors?
- How can I help my baby?
- Where can I get more information about his condition?
- What should I do if I have questions later?
- Where can I get support?

- Can I talk to other families who have a baby with the same condition?



NICU staff do tests to find out about your baby's conditions so they know what treatment your baby needs. Before providers can do certain tests, they need your consent. This means they'll ask you to read and sign a consent form. Sign the form only when you understand the test and why your baby needs it.

## When your baby needs surgery

It can be scary to find out that your baby needs

This resource includes some medical terms you may hear in the NICU. You can find out what they mean in the *Words to know* section at the end of this resource.

surgery. Maybe you knew before your baby was born that he would need surgery, or maybe you just found out. To help deal with your fears and concerns, learn as much as you can before the surgery.

You may be even more worried as the surgery day gets closer. Many families have concerns and questions that come up right before the surgery, but they may feel too nervous to ask them. It's OK to ask any questions you have, even on the day of surgery.

**Here are some questions you can ask about what happens before and during surgery:**

- Why does my baby need surgery?
- Who will be doing the surgery? How many surgeries like this one has the doctor done in the past?
- Where will the surgery take place and how long will it last?
- Will my baby need to skip a feeding before surgery?
- Can I be with and hold my baby before surgery?
- Where can I wait during my baby's surgery, and how will I get updates?
- What resources does the hospital have for families who have a baby getting surgery? Are there overnight rooms available? Are there staff who can support our family?

**Here are some questions you can ask about what happens after surgery:**

- Can I be with my baby right away?
- How is my baby going to feel after surgery? Will he be in pain?
- Where will my baby go after surgery?
- How can I help my baby after surgery?

- How long before my baby wakes up after surgery?
- What will my baby look like after surgery?
- What tubes, lines and equipment will he have?
- How long will his recovery be?
- Will my baby have permanent scars from the surgery?

Watching your baby being taken into surgery and waiting for news can be hard. Before your baby has surgery it can be helpful to make a plan for what you will do during and after his surgery.

**Here are some things you can do to help you cope during your baby's surgery:**

- Tell the staff that you want updates about how your baby is doing during and after surgery.
- Decide who you want to be with you as you wait.
- Decide what you want to do while your baby is in surgery. Make plans to wait in the hospital, take a walk, talk to a friend, read a magazine or watch a movie.

**Here are some things you can do to help you cope after your baby's surgery:**

- Spend time with your baby while he is recovering.
- Decide how you want to let friends and family know about the surgery. This may be an email, text or phone call. Consider having a friend or family member help.
- Ask friends and family to help out at home in the days after the surgery.



Some of the hardest times were kissing our daughter goodbye before surgery. We always felt helpless as we waited, hoping that all was going well. I will never forget how my heart would pound when someone would approach or call with an update. Or when the surgeon would talk with us after the surgery.

It was always a big relief to be back at her bedside, holding her hand. Even though I was able to be with her, I felt worried about whether the surgery had been successful or if she would need another.

## **MARLENA**

MOM OF A BABY WHO HAD SURGERY

## When your baby has a syndrome or birth defect

It can be hard for parents to hear that their baby has a syndrome or birth defect. You may have found this out during pregnancy or after your baby was born. There's no right or wrong way to handle this news. You may want to take time to understand how this diagnosis will affect your baby and family.

Most syndromes and birth defects range from mild to serious. For mild conditions, your baby may have only minor problems. For more serious conditions, your baby's health and development may be greatly affected. Sometimes doctors are unable to tell families how serious a syndrome or birth defect is. They need to wait until the baby begins to grow and more testing can be done.

Having a child with a birth defect or syndrome can create many challenges for parents. It may be helpful to ask questions and get more information. Some of these questions will have answers and some will not.

### Questions for health care providers:

- How did my baby get this condition?
- Can this condition be treated?
- How can we help our baby?
- How will this condition affect our baby's growth and development?



### Questions to talk about with your family:

- How can our family adjust to our baby's condition?
- How do we tell other family members and friends about the condition?
- What information can we share with people we don't know?

### If you've just learned that your baby has a birth defect or syndrome, here are some ways to get more information about the condition:

- Ask your health care team where you can find the most up-to-date information about your baby's condition. They can send you to places that you can trust, such as the March of Dimes at [marchofdimes.org](http://marchofdimes.org).
- Join a support group. Also, check out websites where parents talk about their experiences having a baby in the NICU, such as [shareyourstory.org](http://shareyourstory.org). Ask to speak to other parents who have a child with your baby's condition.

## Notes

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Nathaniel was born with Treacher-Collins syndrome. This birth defect caused him to be born with missing or deformed bones throughout his face. He was born at a hospital that couldn't care for the many needs he had, so he had to be transferred to another hospital that could better care for him. We ended up spending the first 30 days of Nathaniel's life in the NICU.

In the NICU, Nathaniel received wonderful care, and it seemed as if he was loved from the minute we stepped into the NICU. Because of his birth defect, he struggled to breathe and eat. He required multiple surgeries in just the first days of his life. Because of all of the issues Nathaniel was born with, we were two panic-stricken parents who didn't know what to do. It was an emotional experience.

The doctors and nurses in the NICU made sure that Nathaniel got everything he needed. But most importantly, they created a feeling of love and warmth. I am convinced that this helped launch Nathaniel on a life of happiness.

## **RUSSELL**

DAD OF A BABY BORN WITH TREACHER-COLLINS SYNDROME





I knew nothing about premies when Charlie was born at 26 weeks, weighing 1 pound 11 ounces. Having a baby was supposed to be a happy event, but I was scared, heartbroken and full of grief. I was overwhelmed by the strange new world that now surrounded me.

The NICU nurses taught me how to care for my daughter and explained what to expect. The NICU staff supported me on the tough days. After 3 months in the NICU, my baby was well enough to go home. Her discharge day is a day I will remember for the rest of my life.

## **REBECCA**

MOM OF A PREMATURE BABY

## What is Neonatal Abstinence Syndrome?

Neonatal abstinence syndrome (also called NAS) is a group of health conditions caused when a baby withdraws from certain drugs he's exposed to in the womb before birth. NAS most often happens when a pregnant woman takes opioids, like oxycodone, methadone, heroin or other medications. NAS can be caused by medicines that may or may not have been prescribed by a doctor.

Signs and symptoms can be different for every baby with NAS. Most appear within 3 days (72 hours) of birth, but some can appear right after birth or within a few weeks of birth. Signs and symptoms can include:

- Fussiness, excessive crying or having a high-pitched cry
- Trouble sleeping and lots of yawning
- Poor feeding or slow weight gain
- Sucking excessively
- Breathing problems, including breathing really fast
- Fever, sweating or blotchy skin
- Diarrhea or throwing up
- Stuffy nose or sneezing
- Body shakes (tremors), seizures (convulsions), overactive reflexes (twitching) and tight muscle tone

*“It was so hard to see my baby so fussy. I worked with the nurse to learn to care for my baby while he was withdrawing. Being able to comfort my son made me feel more confident as a parent.”*

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### NICOLE

MOM OF A BABY WITH NAS

## How long will my baby be in the NICU?

Not all babies with NAS will go to the NICU. Most babies with NAS who stay in the NICU are there for an average of 16 days. This could be shorter or longer based on your baby's symptoms or other health conditions.

## What care will my baby get in the NICU?

During your baby's NICU stay the staff will make sure he is comfortable and show you ways to care for and comfort him. NICU staff will:

- Use a scoring method to check your baby's symptoms every few hours. Many NICUs use the Finnegan scoring method, which is done at least every four hours.
- Give your baby medicine, if he needs it, to help with withdrawal symptoms. Once these symptoms are under control, your baby gets smaller doses of the medicine over time so her body can adjust to being off the medicine. Medications may include morphine, methadone and buprenorphine.
- Make sure your baby is getting enough to eat. Your baby may be fed formula with extra calories to help her gain weight. Some babies are fed through a feeding tube until they can breastfeed or take a bottle. The feeding tube is put in the baby's nose or mouth and goes into the stomach.
- Order your baby other kinds of care. This may include physical therapy (to help with muscle strength and coordination), occupational therapy (to help her develop skills in moving her arms and legs, feeding and swallowing, and bonding) and speech therapy (to help with feeding problems).
- Do things to keep your baby comfortable, like swaddling her or giving her a pacifier.
- Keep you updated and help you care for your baby.



## How can I help my baby?

While your baby's being treated for NAS, he may be fussy and hard to soothe. Doing these things can help calm him:

- Swaddle your baby (wrap him snugly) in a blanket.
- Give your baby skin-to-skin care (also called kangaroo care). It's when you put your baby, dressed only in a diaper, on your bare chest.
- Keep your baby in a quiet, dimly lit room.
- Breastfeed your baby.

## How can I help myself?

Having a baby in the NICU can cause many feelings like guilt, sadness, fear and anger. It's important to take good care of yourself too, so you can stay well. Doing this will give you more energy to spend time with your baby. Here are some ways to take care of yourself:

- Continue to see your health care providers. If you're taking medicine prescribed by a provider, ask him any questions you may have. Ask if a treatment plan for opioid use would be helpful. If you're in treatment for addiction, continue to follow your treatment plan.

- Have a daily routine that includes taking care of yourself and spending time with your baby.
- Connect with other moms who have had a baby with NAS.
- Ask for help when you need it.

## What about your family's future?

When your baby has long-term health conditions, it can be hard to imagine how you'll cope. A lot of parents struggle with what these health conditions mean for their baby and family. It may be helpful to focus on what's happening right now, instead of on the future. Each day may have different challenges or successes. It's hard to know what the future holds for any baby.

Many parents feel it helps to meet with other families who have faced the same health conditions. You may want to do this while your baby is in the NICU, or you may want to wait until your baby is older. Remember that no two babies are the same even if they have the same health condition.

## Notes

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# Words to know

**birth defects** — Health conditions that are present at birth. They change the shape or function of one or more parts of the body. Birth defects can cause problems in overall health, how the body develops or how the body works.

**diagnosis** (dye-uhg-NOH-siss) — Health problem(s) or condition(s) that the baby has.

**discharge** — When a baby leaves the NICU and goes home or to a step-down unit.

**health care provider** — Also called provider. The person who gives medical care.

**health care team** — A group of health care providers who work together to care for a baby.

**NICU** — Also called the neonatal or newborn intensive care unit. The place in the hospital where newborns go for special care.

**premature birth** — When a baby is born before 37 weeks of pregnancy.

**support group** — A group of people who have the same kinds of concerns. They meet online or in person to try to help each other.

**syndrome** (SIN-droh-m) — A group of symptoms that happen together and indicate a medical condition. Down syndrome and respiratory distress syndrome are examples.