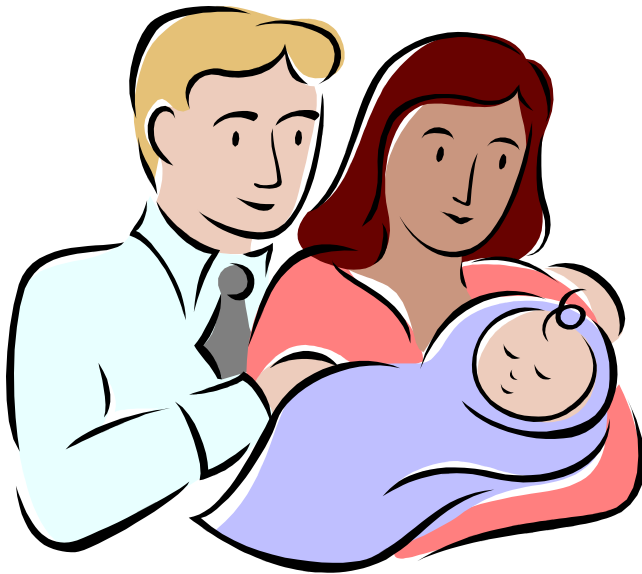


# Hypoxic Ischemic Encephalopathy of the Newborn



## An Introduction for Parents

You have been told that your child has Hypoxic Ischemic Encephalopathy, also known as HIE. We understand that this is a very stressful time for you, and you may be feeling overwhelmed. This booklet is intended to help you understand what has happened to your child, and explain some of the things that will be happening to them.

You may not feel like reading all this information at once. Take your time and look at the sections that you think would help you right now. Save the rest to look at when you are feeling ready.

You may want to use the space at the end of this booklet, or your own notebook to:

- Write down your questions as you think of them. This is easier than trying to remember them when you meet with the healthcare team
- Take notes on what you are told, as you hear it
- Write down names of people you meet and what they do
- Ask healthcare team members to write down information to help you better understand what is happening to your child

Family meetings are held with the healthcare team and whoever you would like to be present. Doctors or nurses may arrange a family meeting, or you may ask for one. At the meeting, the team may update you on your baby's condition or give you additional information. You may also want to use this time to ask questions or clarify any information you did not understand.

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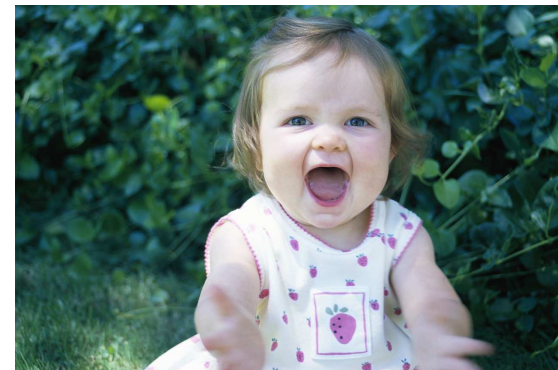
## What is Hypoxic Ischemic Encephalopathy?

Our bodies and brains need a constant supply of oxygen and other nutrients to nourish them. The oxygen and nutrients in our bodies are carried by our blood. If the blood supply is interrupted, or there is not enough oxygen in the blood, the brain becomes “starved” of oxygen. Even if it is just for a short time, the brain may be injured.

*Hypoxic ischemic encephalopathy*, or HIE, is a type of damage to the brain. Hypoxic means not enough oxygen. Ischemic means not enough blood flow. Encephalopathy means abnormal brain function. **At some point, your baby’s brain did not receive enough blood flow or oxygen.** A lack of blood flow or oxygen has caused damage to areas of your baby’s brain.

If the blood or oxygen supply to your baby’s brain has been interrupted, the rest of their body may have also been “starved” of oxygen. This may have caused damage to their other organs, including heart, liver, kidneys and bowels.

Many children have mild effects from hypoxic ischemic encephalopathy, but some have much more severe damage. It is important for you to know that **there is a range of possible outcomes.**



## What happens when the brain is injured?

The brain is like the control centre of the body. It is made up of nerve cells (neurons) that carry messages to and from the body. Together the neurons in the brain coordinate almost everything we do, from breathing to walking.



Neurons receive messages from the body about many things, including what we are seeing or feeling. They also send messages to the body to do things like control our muscles and movement. When these cells are damaged, the brain may not be able to receive and process information from the body, or send messages to parts of the body.

The brain is divided into different areas, based on the functions of the neurons in that region. Some areas involve muscle control and feeling, while other areas are related to vision and hearing. **Depending on the area affected by the lack of oxygen, your infant may have difficulties with the activities controlled by that specific area.** If the damage is widespread, your infant may have difficulties with more than what is controlled by the damaged areas.

The brain is like a network of computers. If a few computers stop working, the rest of the network can take over some of their work. However, if enough computers stop working, the whole system may shut down. In the brain, areas around the damaged part may be able to take over some of the work of the damaged neurons, but they are not usually able to take over the work if large areas are damaged.

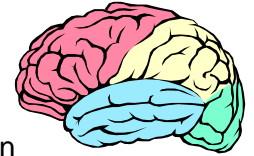
Neurons are one of the few types of cells that cannot repair themselves. Once they are damaged, they are not able to work the way they did before the injury. **The effects of damage to an area of the brain vary widely from person to person.**

## Are there parts of the brain that are more likely to be affected by HIE?

There are many possible areas of your baby's brain that may have been affected. However, the most common areas are the cerebral cortex, basal ganglia, thalamus and brainstem. We have included short descriptions of these for you to better understand what has happened, and what your baby may have problems with in the future.

### Cerebral cortex

The cerebral cortex is the folded outer part of the brain that is usually called the "grey matter". It is involved in many complex brain functions, including memory, senses, thinking, language and consciousness. It is divided into four lobes (sections) according to what each lobe does.



The *frontal lobe* is located just behind the forehead. It is responsible for controlling movement of our arms and legs, helping us plan and do things and controlling our emotions, temper and personality. It is also the area responsible for us being able to speak.

The *parietal lobe* is located behind the frontal lobe, towards the top and back of our head. It receives information from our senses (touch, taste, sight, hearing) and helps us recognize things.

The *occipital lobe* is located at the back of our head below the parietal lobe. This region helps us see things and understand what we are seeing.

The *temporal lobe* is located on the side of our head, behind the ears. It helps us hear and interpret what we are hearing. This is especially important for us in understanding what people say

### Basal Ganglia

The basal ganglia is a group of nerve cells buried deep within the brain. It is involved in starting movements and making sure our movements are smooth.

### Thalamus

The thalamus is located on top of the brainstem. It receives information from our body before passing it on to the cerebral cortex for processing. It also distributes information from the cerebral cortex to the body. It is responsible for how awake and aware we are. It also helps control our emotions and movement.

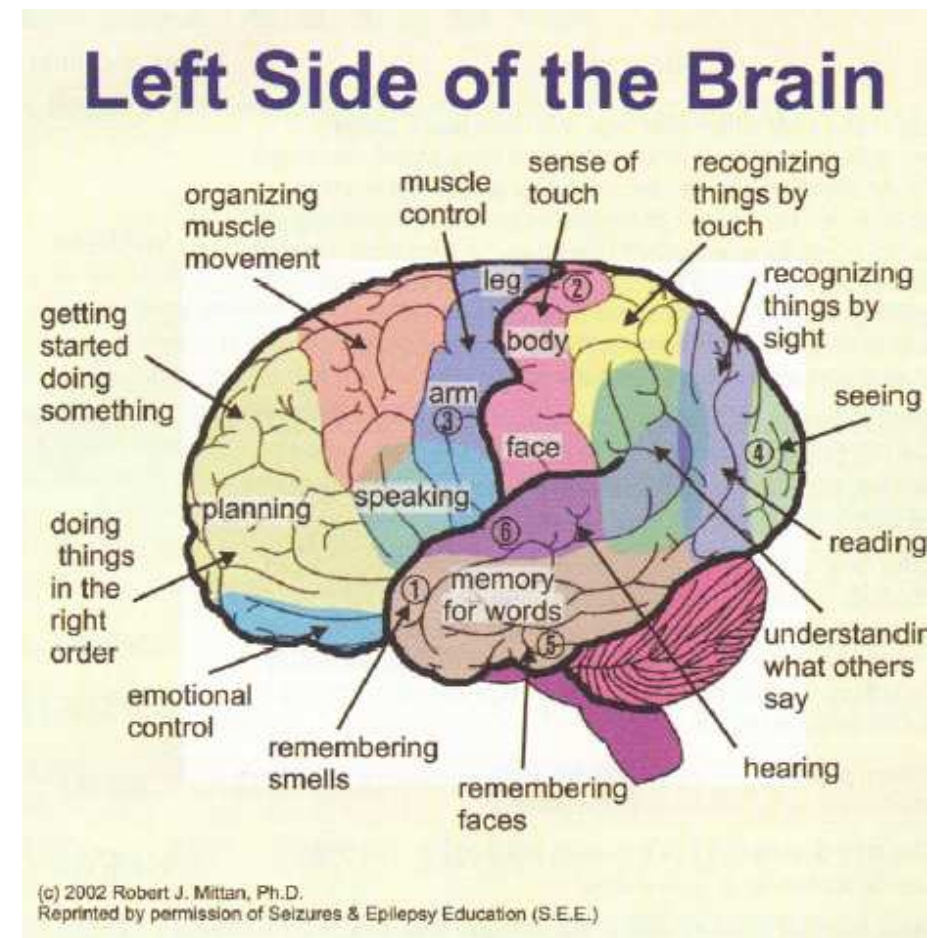
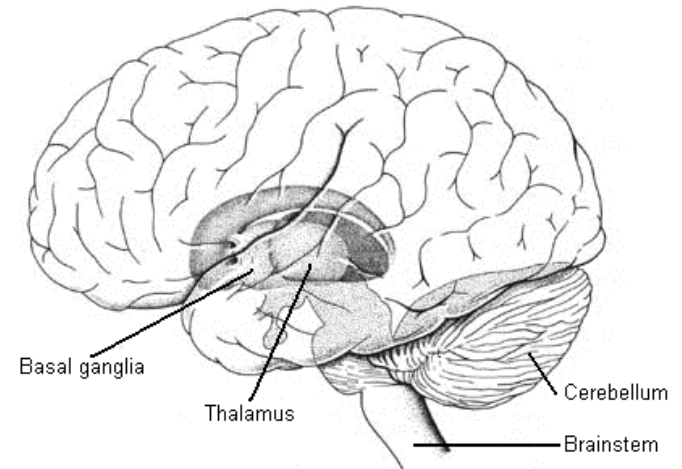
### Brainstem

The brainstem is an important structure that controls many of the things that go on automatically in our body. If you imagine the brain as a mushroom, then the brainstem is the stalk of the mushroom. Some of the things it controls are: breathing, heart rate, body temperature, blood pressure, hunger and thirst.

### Cerebellum

The cerebellum is located at the base of the brain, behind the brainstem. It is responsible for making sure our muscles relax and contract when they are supposed to, and that they have the right amount of tension. It is involved in balance, coordination, and making smooth movements.

The following drawings of the brain may give you a better idea of what is controlled by different areas of the brain.



## How does a baby with HIE act?

You will probably notice that your baby does not act the way you may expect a newborn to act. Some of this may be because of medicine they are receiving. Most of the way they act is because of their brain injury.

They may:

- **be tense and react more to stimulation than most newborns**
- **be floppy and hardly react to stimulation**
- be visually inactive (not establish eye contact)
- have abnormal movements or even seizures
- have problems feeding because their suck is too weak and the muscles in their mouth and throat are not working properly
- have a very weak cry.

Babies with HIE tend to act differently depending on how severe the damage was, and how much of the brain has been affected.



You may also notice that your baby does not respond to you at first. It is still important for you to talk and touch your infant. If your infant is still in the PCCU, you will be able to hold them once they are stable. When they are moved out of the PCCU, it is important that you are involved in their care.

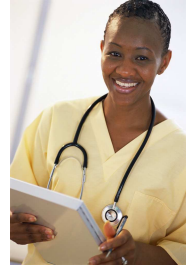
## Why is my baby in the PCCU?

Your baby's vital signs may be abnormal. *Vital signs* are blood pressure, heart rate, respiratory (breathing) rate and temperature. The nurses and doctors will be watching these very closely. They may also notice signs of damage to your baby's organs such as the lungs, heart, liver, kidneys, or intestines.

Your infant may need some extra help with breathing. They may need special medications to keep their blood pressure normal. Their condition may be unstable, or even critical, and needs some extra monitoring. **The PCCU has specialized staff and equipment, and is designed to be able to closely monitor and care for your child 24 hours a day.**

## What will happen in the PCCU?

Your child will probably have some tubes and machines attached to them. These may look scary or frighten you. The healthcare team will be close by to care for your baby and answer your questions.



**Your child's breathing will be closely monitored.** If they have problems breathing on their own, they may need to be *intubated*. This means that there is a tube inserted into the airway, and is attached to a machine that will breathe for them. This is usually only temporary.

**Your child will be having many tests done** to find out which areas of their brain and other organs have been affected. The three main types of test that will be done to assess your baby's brain are: physical exam, pictures of the brain (for example MRI and CT), and brain function tests (for example EEG).

These tests help the healthcare team figure out the best plan of treatment for your child. They also give the team a better idea of what your baby may have problems with as they grow up. Keep in mind that these are just guidelines, and each child is different.

Some of the common equipment, medications, and tests that your baby may have are described at the end of this booklet.

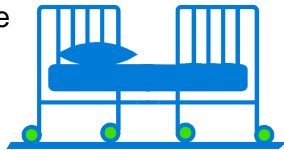
While your child is in the PCCU, you will probably have many questions. Nursing staff are always close by, so you may want to ask them some questions. You are encouraged to be as involved in your child's care as much as is safe. Parents may visit the PCCU at any time of the day or night.

**When your child is first in the PCCU, their condition may be very unstable.** At this time, you may not be able to touch them. However, you can still be with them and talk to them. Your child may not be able to breastfeed, but ask the PCCU staff about breast pumps. You may be able to bring in pictures or stuffed animals to put you're your child. Talk to your nurse about how you can be involved.

When your child is more stable, you will be able to touch and hold them, even with the IV and other equipment. As they improve, you may be involved in bathing and changing them.

### **What happens when my baby starts to improve?**

Your child will be moved out of the PCCU when they have stable vital signs and are in no immediate danger. Usually this means that they must be: breathing on their own, able to keep their airway clear, and tolerate feeding. At this time, **they will be moved upstairs to a paediatric inpatient unit.**



On the unit your child's vital signs will still be monitored, especially for signs of seizures and "A's and B's". "A's and B's" are times when they stop breathing (apnea) or have a slow heart rate (bradycardia).

Many children with HIE have problems with feeding by mouth. If your baby is not yet ready to drink from a bottle or breast, the feeding team would work on skills to get

them ready for feeding. These skills include encouraging your infant to stay calm, and to control their breathing and heart rate when being moved and held. They may also include coping with touch to the face and mouth and strong sucking on a pacifier or finger.

As your baby's condition continues to improve, you will be encouraged to participate more in their care. For example, you will probably be involved in bathing, changing, and feeding them.

### **When will my baby be ready to go home?**

Your baby will probably be ready to go home when they are able to feed safely, gain weight consistently, and have normal breathing and heart rate (no "A's and B's"). If they have had seizures, their seizures must be under control.

### **How will my child be when they are older?**

There is a **wide range of outcomes for children who have hypoxic ischemic encephalopathy.** Some children have no lasting effects from HIE. However, others will have mild disabilities, and some will have several serious effects. The range of outcomes depends on many things, including: how severe the injury was, the type of injury your child had, the areas of the brain that were affected, and the stage of development your child was at when they had the injury.



Children with the least amount of damage to their brain tend to do as well as other children in school, and have minor or no neurological problems. Children with a lot of widespread damage usually have the most problems.

Some of the **more common problems** are:

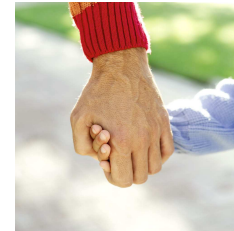
- Problems with muscle tone (too much or too little tension in the muscles)
- Problems with coordination or fine motor movements
- Memory problems
- Feeding problems
- Attention deficits or behavioural problems
- Learning disabilities (for example, problems with spelling, math, reading)
- Cerebral palsy
- Hearing disabilities
- Visual difficulties (for example, cortical blindness – see below)
- Seizures

If your child has movement or tone difficulties, you will probably hear the term *cerebral palsy* used in relation to them. Cerebral palsy is not a disease, but is a group of disorders that affect motor movement and coordination. Many children with HIE will be diagnosed with cerebral palsy because there is damage to the brain areas that coordinate movement. Problems with muscle coordination can affect not only standing and walking, but also speaking and eating if the facial muscles cannot be coordinated.

Another condition that sometimes affects children with HIE is *cortical blindness*. This means that a child cannot see, but their eyes are not physically damaged. When we see something, the information that comes through our eyes is passed on to the cerebral cortex of our brain for processing. If the area that processes this information is damaged, we are not able to recognize what we see.

A child with cortical blindness has had damage to their brain and is not able to process what they are seeing.

Keep in mind that there is a wide range of how these problems affect people. Also, a lot of the ability to adapt to any problem(s) your child may have will come from you.



**A positive attitude about who your child is and what they can do will help them have the strength to cope with problems they may encounter.**

Finding out what their needs are, and making use of the resources that are available, will help them achieve their maximum potential. You may want to look at some of the resources we have listed at the back of this book, or ask your healthcare team for suggestions.

### **Who are the members of the healthcare team?**

By now, you have probably met many new people. It may be very difficult for you to keep track of who is who and what each person's role is. Team members will be introduced to you and your child early on. **They will work together with your family to achieve the best possible results for your child.**

Some of the team members you may meet are:

#### *Intensivist.*

An intensivist is a paediatrician who specializes in treating critically ill children. They assess and treat acute problems with breathing, cardiovascular system or other organ systems. The intensivists work with the rest of the team to care for your child while they are in the PCCU.

*Paediatric Neurologist:*

The neurologist is a paediatrician who is an expert on the developing brain and how the nervous system functions. The neurologists work with the rest of the team to provide medical information and make a plan of care.

*Paediatrician (CTU):*

A paediatrician is a doctor who specializes in treating children. At the Children's Hospital, a group of doctors known as the CTU (Clinical Teaching Unit) lead the team of residents (doctors training to become specialists). "Rounds" is when this team comes by to check up on your infant and make a plan of care. This can be an excellent time to meet with the team.



*Nurse Practitioner:*

The nurse practitioner is a specialist in brain disorders. The NP assesses the comprehensive needs of your child and works with the health care team to develop a plan of care that includes the needs of your family. They help you navigate the health care system so the ongoing needs of your child are met.

*Registered Nurse (RN):*

Nurses work with the team to assess how your child is doing, plan your child's care and treatment, provide care on an ongoing basis, and teach you various aspects of care to help you get your baby home.

*Respiratory Therapist (RT):*

The respiratory therapist assesses and helps treat any problems your baby may have with breathing.

*Pharmacist:*

The pharmacist works with the healthcare team to make sure that your baby receives the most appropriate drug treatment.

*Social Worker:*

The social worker is available to provide supportive counselling about emotional, financial, family and other related concerns. They can also help with information about community resources and/or financial programs that are available.

*Feeding Team:*

The Feeding Team includes the speech-language pathologist and occupational therapist. They assess how well your baby is able to manage sucking, swallowing, and breathing at the same time. They will work closely with the team to make a plan to meet your baby's special requirements.

*Dietitian:*

The dietitian assesses if your child has any special dietary needs, and makes sure they are receiving the right kind and amount of food for them.

*Physiotherapist and/or Occupational Therapist:*

These therapists assess how well your baby holds and moves their head, arms and legs. The therapist will also look at how your baby responds to movement, sound, and touch.

*Spiritual Care:*

The spiritual care team can provide help with your spiritual, religious, emotional and moral needs. They are interfaith professionals who can respond to your spiritual and religious needs during times of distress and crisis, celebration and life change.



## What is all that equipment?

There may be many tubes and lines attached to your child. They may look frightening, but we hope that understanding why they are being used will make them less intimidating. Please remember that your child may have all or none of these, depending on the monitoring and treatment they need.

### Cardiorespiratory Monitor

This looks like a small television that is attached with wires to your child's chest and abdomen. It constantly monitors heart rate, breathing rate, oxygen level in the blood and blood pressure.



### Intravenous (IV) Lines

The IV is a small flexible tube that is placed inside your child's vein. Through this tube, medication and fluids can be given directly into their vein. An IV may be placed in their hands, feet, arms, leg, or scalp.

### Umbilical Lines (Arterial or Venous)

After birth, the arteries and veins that went through the umbilical cord can still be easily accessed. The healthcare team may insert a small flexible tube (catheter) into the artery or vein. This lets the team access your child's artery and vein many times without having to poke them each time.

### Tracheostomy Tube

A "trach" tube is a special tube put into a small hole in your baby's neck. In rare instances your baby's brain may be damaged in such a way that they are unable to keep their airway clear of mucous or saliva. They may not be able to cough, swallow, gag or even do all three. In this case, a tracheostomy tube would be inserted to help them breathe and protect their airway.

### NG, G and G-J Tubes (Naso-Gastric, Gastrostomy, Gastro-Jejunostomy Tubes)

If your child has trouble with feeding, they may need to be fed through a tube directly into their stomach. In the short term, a tube may be inserted through their nose and into the stomach. This is called a naso-gastric (NG) tube. If your child will need to be fed through the tube for a longer time, a tube may be inserted directly into their stomach (gastrostomy tube) or small intestine (gastro-jejunostomy tube).

## What are all those medications?

Your baby may receive different types of medication. If you have questions about any of the medications that your child is on, ask your nurse or doctor.

- *Sedatives* (ex. Midazolam) help to reduce anxiety, make muscles relaxed and keep your child asleep if they are intubated.
- *Narcotics* (ex. Fentanyl) are given to manage any pain your child may be having and to help them stay asleep while they are intubated.
- *Inotropes* (ex. Norepinephrine) help keep your child's blood pressure and heart rate normal and help their heart work better.
- *Anticonvulsants* (ex. Dilantin, Phenobarbital) are given to treat seizures.

## What tests may be done?

The healthcare team will use the results of these tests to better understand what areas in your baby's brain have been affected. Your doctor will decide which test is best to determine what is happening to your baby.



**Sometimes your infant may have a series of these tests until the healthcare team is sure of how they are doing.** It may be important to you and your family members to look at the results of these tests so you can see the areas of your infant's brain that have been affected. Be sure to discuss with your healthcare provider if this is something you would prefer to see.

*MRI (Magnetic Resonance Imaging):*

An MRI is a test that uses a large magnet, radio waves, and a computer to make images of the inside of your child's head without using radiation. A special MRI may also be done to look at the arteries (called an MRA) or veins of the brain (called an MRV). This test is painless and usually takes about 30-90 minutes.

*CAT Scan (Computerized Axial Tomography):*

A CAT scan (also called a CT scan) uses x-rays and computers to generate detailed images of the structures of your child's brain. This test is painless and usually takes about 15-20 minutes.

*EEG (Electroencephalogram (ee-lek-tro-en-seh-fah-lo-gram)):*

The EEG is a test that picks up electrical impulses from the brain and records them in a series of wavy lines. This test is painless, and lasts for about 45 minutes. This test will help the healthcare team members better understand what, if any, brain activity has been affected.

*Cranial Ultrasound:*

This test is the same as the ultrasounds that pregnant women have to look at their baby before it is born. In this case, it is used to look at images of your baby's brain.

*Blood work:*

Your child's blood will be drawn so that the healthcare team can have a better idea of what is going on inside your child's body. Blood is tested in the lab to determine how your child's organs and medications are working.

**What can I do?**

This is certainly a very stressful time for you. You may feel that you need to be with your child all day and all night. This is normal. However, it is important to take time to look after your own health.

You will probably need some time to begin to heal emotionally. If you have just given birth, you will need time to heal physically as well. Try to remember to **take care of yourself so you can be at your best when you are with your child.**

Here are a few things to keep in mind:

- **Get some rest.** If you are from out of town, you may want to find out more about Ronald McDonald House.
- **Remember to eat.**
- **Ask for help.** Ask your family or friends to help out with chores or just to be there for you. If you feel you need more help than your family and friends can give, talk to the social worker or other members of the healthcare team about resources that are available for you.
- **Take shifts.** You may feel more comfortable leaving your child's bedside if another family member is there with them. Let the PCCU staff know who will be coming to be with your child. This is a great opportunity for you to get some sleep and something to eat.
- **Bring in things from home.** You may want to bring in pictures, blankets, stuffed animals or tape-recorded messages to be with your baby when you are away from them.
- **Ask questions.** If there is something you do not understand or would like more information on, ask one of the members of the healthcare team

**We understand that this is a tough time for you. The healthcare team is here to help you, as well as your baby.**

## What have other families said?

Many parents provided input in creating this booklet. Many of them went through experiences similar to what you are going through now, and felt the way you do. We have included some of what they said. We hope that their words can give you some comfort and hope.

- Looking back, we were scared at first. It was so overwhelming.
- We just needed time to absorb and digest all the information they gave us. So much at once was exhausting. I know they need to tell us all the medical stuff, but it was so much at once.
- The information we received was so strange and so new. It wasn't what we wanted to hear, but looking back we are glad that we did hear it because it was the truth.

If you are feeling the same way these parents did, you may want to try some of these strategies:

- Write questions down as they come up. You may not remember them later.
- Write down exactly what is said. This way you can read it over later, when you are feeling better able to process the information.
- If you are feeling overwhelmed, ask someone to take notes for you.
- Ask for several shorter meetings with the healthcare team, rather than one long meeting. It is important for you to get information at your pace.
- Our family has a lot to be thankful for. With my child you can't rush, but every time she makes progress, it is so encouraging for us. Time doesn't matter.

- To us, God has been our help; we get our strength through him. It doesn't have to be God though; others find help in different spiritual ways.
- It is helpful to network with other parents and families. Support groups can be so helpful, to make you feel connected and to answer your questions. To have someone who really understands what it is like is important. To see that others have and can do this, that is important.
- In life there are always questions that just have no answers.
- I know my child isn't perfect, but to me he is perfect in his imperfection. I never knew I would love him so much, and that he would love me so much in return.





