

The Journey With Your Baby!

Welcome to NICU

Call NICU any time at: 237-2775

The Neonatal Intensive Care Unit, or NICU provides care for newborn babies. Parents are the most important people in a baby's life. In NICU we support family centered-care. We hope that this booklet will help you feel like a part of the team looking after you baby. It will give you some answers to these questions:

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How do I keep my baby safe from germs?

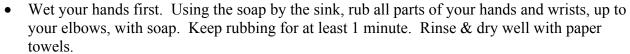
Please help us keep babies safe from illness which may be prevented. Sick or premature babies get very ill if they get germs which cause minor illness in adults and older children. *All visitors must review the "Attention NICU Visitors" Screening chart on the unit door before each visit.*

You are the best person to make sure that all people who come to see or work with your baby do not spread germs. You can learn what you need to do, and teach the people whom you bring with you. You can also watch others who come to your baby's bed to make sure they do the

same. We want you to feel that you can ask people to wash their hands if you think they have not done it well enough. We will do the same

The most important thing to do is to wash your hands the right way and make sure that each person that touches your baby does so as well. When you come to visit and before you touch your baby:

- Remove your rings, bracelets and watch.
- *Wash your hands* well. It is best to use the sink that is just inside the entrance to NICU.



• If you use the gel hand cleanser, put some in your hand (the size of a dime) and rub your fingernails from the other hand in it. Move some to that hand and rub the fingernails of the other hand in it. After that make sure that you cover all parts of your hands, wrists and between your fingers with the cleanser. Your hands must be dry before you touch your baby.

To keep your hands clean after they are washed:

- Do not touch your face, hair, chairs etc.
- If you touch something that is not "clean", such as your purse, jacket, doorknob, chair, or something that has been dropped on the floor, you must wash your hands again before you touch your baby.
- Use a paper towel to touch anything that has not been washed.

If you do not feel well, talk to your nurse before you come in. You may need to wear a hospital mask. Anyone who is coughing a lot, or has diarrhea, should not be in the unit.

During cold and flu season, children may not be able to visit because of the risk of colds being given to the babies.

Anyone who has been in contact with an illness such as chicken pox, measles, mumps or shingles must phone the unit before visiting.

Before you leave the unit, you must wash your hands again.



How will I cope?

Coping with this time in NICU can be hard. We will do what we can to help you. We take care of the whole family, not just the baby. We will help you find support to meet your needs. You may also find help from your family, friends, church or other groups that you are a part of. Sometimes talking to other parents in the unit helps. Talk to your baby's nurse about the things that you are finding hard to deal with. Some concerns that you may want to talk to the nurse or social worker about may include:

- someone to care for your other children
- finding a way to get to the hospital
- dealing with your own health
- concerns about other family members

You will hear many new words used. This book will help you to define as many as we can. There is also a glossary that you can pick up in the unit. It is filled with words that you might hear or read about. Please ask a nurse for it if you wish to read it. Also, please ask the staff to define words that are new for you.

Can I talk to someone who has been here before?

You may wish to talk to another parent who has been through the NICU with their baby in the past. We offer a program where you can be matched with a "buddy" who has had a baby who was similar to your baby. This program is called the Neonatal Family Support Program. The parents who volunteer in the program have all been given some training and have been screened by the hospital. They are part of the team looking after you. The reason that they are working in this program is to let you know that you do not have to go through this alone. They know how hard it is to talk to someone who does not know what it is like. It may even be hard to talk to your partner or family members about how you feel. Please think about talking to a parent who has been here before. It may help you get through this hard time.

The back page of this book is an application that you can tear off. There are also some in the unit. You can ask your nurse or social worker about it, or call 787-1786 to leave a message with your name and phone number. Fill out the form and give it to your nurse. Your phone number will be given to one of the parent volunteers who had a child similar to yours. They will call you. They will talk to you about how they can best help you through this time. You can talk to the nurse or social worker about the program at any time. You can ask for a support person before your baby is born, or any time after your baby is born. You may even ask for a support person after you go home.

You may wish to be a volunteer in this program in the future as well.



"Learning the Ropes"

The staff is around all the time to watch your baby. The hospital has students who are also watched closely so that they can learn from the staff and the babies.

We try to keep the lighting at lower levels, or use a cover over your baby's bed or eyes. This helps baby to sleep better. We also try to keep the noise levels in the NICU as low as possible. You can still talk to your baby in a quiet voice. Babies like a soft soothing tone.

When can I come?

- Parents or guardians are part of the team, and you may come at any time.
- Parents are asked to list 4 main visitors when their baby is admitted to NICU. The names of the 4 visitors will be written on a card kept at baby's bedside. We do not allow any visitors in the unit unless you are with them. Non-parent visitors must come during visiting hours 1:00 PM 8:30 PM.
- When you come to the unit, please use the phone on the wall in the circular glassed-in area outside the entrance to NICU. Tell us your last name and your baby's last name and we will unlock the door for you.
- You may have up to 2 people at the bedside at a time. One of them must be a parent. If you have more people with you, they are welcome to use the parent lounge in the hallway until it is their turn to come in.
- Most of the time, when we are giving your baby care, you can be there. There may be times when a procedure is being done for your baby or one of the other babies in the unit. We may ask you and your visitors to wait in the lounge while it is going on. There may also be times when you may choose to leave while something is being done. We will call you back when we are finished. If you do not understand a reason for being asked to leave, please talk to the nurse about it.

Can I bring my other children?



- Baby's brothers and sisters are welcome as long as they do not have a cold or other illness that could be passed on to the baby. Show them pictures before they come to help prepare them for the visit. Talk to them before they come about washing their hands. Prepare them for how the baby will look and what they can do. They may be able to touch the baby, but must not touch the equipment. If the children are prepared, it will make the visit easier for you as well.
- You can help your other children cope with this time by having them draw

pictures to put on your baby's bed. Tell them what is going on and that they are an important part of the family.

- We do not allow other children (under age 12) to visit in order to help keep germs away from the babies. Children are more likely to have colds and runny noses. These can easily be passed to the babies in the unit by small hands.
- Baby's brothers and sisters may visit once a week.

About Privacy

We work to protect the safety and privacy of all babies in the NICU.

Information about your baby will be shared with members of the health care team who are caring for your baby. We will not tell anyone else about your baby. Please ask your family and friends to call you to find out about your baby. Please do not give out the unit phone number – it is for your use only.

There may be times when you hear things that are said about other patients. If this happens, please do not share this with anyone else.

Taking pictures of other babies or staff members without their permission is not allowed.

How can I be part of the team?

- You are the center of your baby's life.
- You are an equal partner with the team in the unit.
- We respect your beliefs and culture.
- You may take part in decisions about your baby's care.
- You can work with your baby's nurse to find out what you can do for your baby.

How can I be a parent here?

Small or sick babies do not like loud noise, bright lights or lots of touching. When stressed by these, they may show us "time out" signs such as:

- Changes in heart rate or breathing
- Yawning
- Hiccups
- Fussing
- Crying
- Not making eye contact
- Holding arms out straight
- Spreading out fingers and toes

This does not mean that you cannot touch or talk to your baby at all. It is important that you *do* touch your baby. Your baby wants and needs this from you. The staff in the



NICU will help you to learn how to is important that you *do* touch your baby. Your baby wants and needs this from you. The staff in the NICU will help you to learn how to tell when your baby is ready to hear your voice or feel your touch.

Almost all babies can handle gentle, firm touch given to them by their parents. Often this can help to calm a baby. They do not like as much touching as a healthy term baby. They also do not like light, tickling motions on their body. What works the best is to lay a hand gently but firmly on the baby's arm or leg, or along their chest or back. Babies like to be in a tucked or "curled-up" position, like they were in the womb. This calms them.

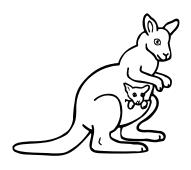
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your baby to show family members and to have as a keepsake.

Your baby may not like more than one thing at a time. Your baby may not like being touched and talked to at the same time, and may show some of the time-out signs. If this happens, stop what you are doing, and do just one thing at a time. Your baby's nurse will help you to read your baby's signals. If you like you may bring a camera into the unit. Take pictures of

You may bring a toy, tapes, and pictures of family members to place at your baby's bedside. Please label these with your baby's name so they do not get lost. Do not put dirty clothes that belong to you in the hospital laundry bin – they may get lost! Leave jewelry and other valuable items at home.



You will be able to hold your baby when he or she is well enough. Kangaroo care is a comforting way of holding babies. Ask your nurse to help you hold your baby this way.

Some parents find it easy to touch and cuddle their baby; some do not. It is normal

to feel anxious about touching your baby. The nurse can teach you how to touch your baby in a soothing way. When your baby is well enough, you can do things such as mouth care, diaper changes, and bathing. Bath time is a good time to learn about how to care for your baby. It is also a sign that your baby is getting better.



How can I get information?

We want to make sure that you learn as much as you can about your baby. We welcome all your questions. Please give us a phone number where we can reach you or leave a message for you. Parents or guardians may phone us at any time: 237 2775.

You are part of the team that makes decisions about your baby. This is often done during "rounds", a time when the medical team meets



each day. We talk about how your baby is doing and the plan of care. We also talk about problems that may arise and how to deal with them. We will talk about things that happened to your baby before, during and after birth. The nurse will talk about what has happened over the past day. Other members of the team will talk about their aspect of your baby's care. You will be asked to tell us how you feel things are going with your baby and if you have any questions or concerns. Please tell us. If you have concerns and questions that need more time to answer, we will arrange to continue the talk after the end of rounds. Rounds take about 2 hours to complete. The team moves from bed to bed and spends between 5 - 15 minutes at each one. When we reach your baby's bedside you will be asked to join us.

Rounds usually start at 9:00 am.

You can talk to the nurses at any time. Ask questions if you do not know what is happening or how things are going. You can also talk to the doctors. There is almost always a doctor present in the unit. There is always one doctor (neonatologist) who is in charge of the unit. If you wish to speak with a doctor, your baby's nurse will contact them for you. You may also phone your baby's pediatrician for updates on your baby.



There is written information on many topics that might be of interest to you. If there are things that you would like to read about, ask your nurse. You can also find information at the Family Information Library at Children's Hospital CK204. It is there for families all over Manitoba. They loan books and videos on many aspects of child health care. You are welcome to visit the library. You can also ask them to send it to you. To talk to the librarian, call 787-1012.



What can I expect?

When your baby comes to NICU the doctors, nurses and other members of the health care team give your baby the care he or she needs. This may include:

Monitoring

Sensors may be taped to your baby's skin to give information about heart rate and breathing. This can be seen on the monitors. Your baby may have a small tube put into an artery or vein to measure blood pressure. You may hear beeps and alarms often. They sound to alert the nurse of something. Most alarms are not urgent. Many happen when your baby moves or changes the way they are breathing as they wake up or go to sleep. Nurses attend to the alarms as quickly as they can. The nurse will also monitor your baby by checking "vital signs" at regular times. This includes heart rate, blood pressure, temperature and reading the numbers on the machines.



Tests

Your baby may have some or more of the following tests:

Blood tests – Your baby's blood can be tested for many things that tell us how well he or she is doing. Blood can be taken from a needle placed in a vein or artery. It may also be taken by pricking your baby's heel. There are some common tests that may be done:

- Blood gases tell us about your baby's breathing.
- A blood count or CBC tells us how many blood cells your baby has and whether there may be an infection.
- A blood culture can tell us more about infections in the blood.
- Electrolyte tests tell us about the type of fluid your baby needs.
- These are the most common blood tests that you will see done. There are many other tests that may be done on blood from your baby. Your baby's doctor or nurse can explain them to you when they are done.

Eye exam - A look at the blood vessels in the back of your baby's eyes to see how they are doing as they mature.

Hearing test – A test using sound to check your baby's hearing.

"Picture" tests – There are a variety of ways that we may take pictures of the inside of your baby's body. These include:

X-rays- the most common ones are done to look at the lungs.

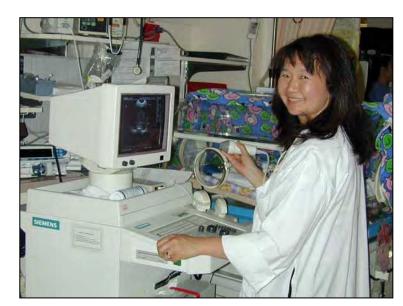
Ultrasounds – the most common ones are done to look at the brain or belly. Most premature babies will have an ultrasound of their brain when they are one week old or sooner.

CT Scans – the most common ones are done to look at the brain.

MRI Scans – the most common ones are done to look at the brain.

These may happen at any time of the day,

and often during the night as well. We will do our best to tell you when tests will be done. The doctor will let you know about results as soon as we can. Talk to your baby's nurse if you would like to be with your baby during a test.



Treatments

- *Tube feedings* Feedings are given through a small tube passed into one nostril or through the mouth and down into the stomach. This is called a "naso or oro-gastric tube".
- *Intravenous* An "IV" may be placed in one of your baby's veins. Fluids and nutrition can be given through it. Usually a hand or foot vein is used. A vein in the scalp may be used. If so, this means that a small amount of hair may need to be shaved.
- *Medicines* The most common are antibiotics, given to treat an infection. There are many medicines used to help babies. Your baby's nurse can tell you about the ones your baby is getting.
- *Central line* It may not be possible to use a regular IV to give your baby the fluids and medicine that he or she needs. A longer line, called a "central line" may need to be placed. This will stay in place and last longer than an IV.
- *Bladder catheter* This is a small tube that may need to be placed into your baby's bladder. This helps us to see how much urine your baby is making.

Breathing help

If your baby has trouble breathing these are some of the ways we can help:

- *Nasal prongs/cannula*: Small soft tubes are placed into your baby's nose to give extra oxygen.
- *Nasal CPAP*: Tubes are placed into your baby's nose through which a small amount of pressure is given.
- *Ventilator*: A breathing machine that moves air and oxygen into your baby's lungs. The air goes in through a tube called an "ET tube" placed through your baby's mouth into the windpipe leading to the lungs.

There are some things that we will not do until we have talked to you and you have agreed to it. We will talk to you about the risks and benefits as well as the options that you have. The surgery or procedure will not be done until you have had all your questions answered and have signed a consent form. In some cases when you are not able to be in the hospital, consent can be taken over the phone.

Times when we will ask for further consent include:

- surgery
- tests that need dye to be infused
- blood transfusion
- medicines that are on trial
- immunizations

In an emergency, a procedure may need to be done without your consent if it would harm your baby to wait.

How can I feed my baby in the hospital?

If your baby is sick or very tiny, your baby will get nutrition in the IV. At first your baby may receive mainly sugar water for calories. If it appears that your baby will not be able to be fed for a few days, he or she may be given *total parenteral nutrition (TPN)*. With TPN, protein, fat, sugar, vitamins and minerals are added to the fluids that the baby receives in the IV. Your baby can get healthy and grow on TPN alone. As your baby is able to take other feedings, the TPN will be decreased.

Your baby may be started on tube feedings. A tube is passed through the mouth or the nose into your baby's stomach. Milk is put through the tube every 2 or 3 hours. This is called *gavage feeding*. The amount will be very small at first and slowly increase. As the amount of milk goes up, the amount of TPN goes down.

Babies have a need to suck. When they are being tube fed it is important that they learn to relate sucking to feeding. This is done by giving them a soother during a tube feed. This soother does not prevent your baby from sucking on the breast when they are ready. Even if a baby is not getting milk feedings, it is important that he or she learns to suck on a soother, so they can practice to be ready for breast or bottle feedings they will do later.

Breastmilk is the best and many babies who have been very sick go home breastfeeding! Breastfeeding is best for the baby because:

- Breast milk protects your baby from infections.
- Breast milk is easier to digest "human milk is meant for humans".
- Breastfeeding encourages you and your baby to bond.
- Breastfeeding ensures lots of skin-to-skin contact with your baby.
- Breastfeeding is easier for your baby than bottle feeding.
- Premature breast milk is specially designed for the premature bowel it is less irritating to the bowel and decreases growth of bacteria.
- It is easier for your baby to manage the flow of milk from the breast than from the bottle. The flow is slower and gives your baby a chance to pause for breaths. As well, the flow of milk stops when the baby stops sucking on the breast, but with the bottle the flow keeps on.

If you choose not to breast feed, or are unable to, there are safe formulas to feed your baby. In the hospital your baby may be given a special formula, but most babies can have regular baby formula when they go home. Each type must be mixed exactly the way it says on the can or bottle. If you need help with this you can call your public health nurse or your baby's doctor.

Will I be able to breastfeed?

We will help you to breastfeed your baby. Most mothers who wish to breastfeed can, even if their baby is born very early, or is in the hospital for other reasons after birth. Some babies may not be able to breastfeed right away because of their illness, but almost all babies can be given breastmilk.

Steps to Breastfeeding:

- Step 1: It is very important to establish your milk supply by using a breast pump.
- **Step 2:** When your baby is ready to be fed, your milk will be used. Most often this is done by tube feeding your baby.

To help your baby's digestion, a cotton swab stick can be dipped into your breast milk and your baby can suck on it. The nurse will show you how to do this.

The milk you produce during the first few days after birth is called "colostrum". This milk is best for the first feedings. It is best to feed fresh milk to your baby as much as possible. If your fresh colostrum or breast milk is not used, it can be safely frozen.

- **Step 3:** When your baby is stronger and ready to eat on his or her own, you and your baby will start having "breastfeeding practice" sessions. Our goal is to teach your baby to breastfeed before other types of oral feeding.
- **Step 4:** When your baby is closer to being ready to go home, you will do more of his or her care. This includes more breastfeeding. Before your baby goes home you will start a breastfeeding plan that will continue at home. Most premature or sick babies are not ready to fully breastfeed at discharge. As they get bigger and stronger at home, they will be able to fully breastfeed.
- Step 5: After you go home there are people who can help you and will answer your questions.

If you have any questions be sure to ask your nurse, or a Lactation Support Nurse (LSN) at the hospital.

When will my baby gain weight?

Almost all babies lose weight after birth before they begin to gain weight. This weight loss is usually 5-7% of the baby's birth weight. Much of the weight loss is loss of excess water the baby was born with.

Sometimes very sick babies gain weight in the first few days. This is not real weight gain, it is retention of water. As the baby gets better, the baby will lose weight. Most often a baby does not regain birth weight until two or more weeks of age.

When can my baby eat?

When babies are born early their sucking is not well matched with their breathing. At about 34 weeks of gestation this suck / swallow / breathe pattern usually matures enough to safely breast or bottle-feed. However, there are big differences between babies. Some are ready at 32 weeks or sooner. Others are not ready until 36 weeks. Nurses can often tell when a baby is getting close to this time by how he or she acts during a tube feeding and how well the baby takes a soother. At first your baby will have only one or two breast or bottle feeds a day. This will gradually increase as your baby gets used to the work of feeding. Babies who have had severe breathing problems may be slower to start and slower to progress with feedings.



Will my milk "come in" if baby is not feeding?

The following steps will make sure that your milk "comes in":

- Begin pumping breast milk within the *first 4-6 hours* after your baby is born.
- Obtain an electric breast pump to use at home as soon as possible. Talk to the nurse about this.
- Pump as regularly as possible every 3 hours or 8 times a day, including once at night.
- During the first couple of days you will get a few drops to about half an ounce (15 ml) each time you pump. This is a normal amount of milk for a baby. Pump for about 10 minutes on each side (or 10 minutes total if you are using a double set-up) even if you are only getting small amounts of milk.
- After 3-5 days you should see a gradual increase in milk. By the time your baby is about 1 week old, you should be pumping about 350-500 ml (1/2 litre) per day.
- Frequent pumping helps to stimulate milk production.

Every drop is as precious as gold!

For more information about Breastfeeding see the booklet "The Journey to Breastfeeding"

Will my baby need a blood transfusion?

Your baby may need to have a transfusion to replace certain parts of the blood that are low. Blood carries oxygen to the body, fights infection and controls bleeding. A transfusion is when your baby receives blood or a blood product through an intravenous (IV).

After a baby is born, the making of red blood cells slows down for a few weeks. Even if a baby is born with a normal amount of red blood cells, there are some common reasons why babies need a transfusion:

- Blood is taken for tests.
- An infection may decrease the making of red blood cells.
- An operation may cause your baby to lose blood.



What are blood products?

A blood product is part of whole blood. Whole blood is blood as it comes from someone who donates the blood. Whole blood can be separated into blood products. Your baby may need one or more of these products. The most common are:

- **Packed red blood cells**: the most common blood products needed. Red blood cells carry oxygen to all the cells in the body.
- Platelets: help blood to clot.
- **Plasma**: the pale yellow liquid that carries blood cells. It contains clotting factors, which help blood to clot and stop bleeding.

There are other blood products which your baby may need. The doctors and nurses will explain them to you should your baby need them.

Where does the blood come from?

The blood comes from the Canadian Blood Services. Blood is collected from donors who offer to give their blood for free.

Before giving blood, donors are asked a long list of questions and have an interview with a nurse.

What are the risks?

The safety standards for the blood supply are very high. Each unit of blood is tested for many known diseases. Blood is not used if there are any concerns that it may transmit disease. There is still a very small chance of getting a disease or virus from donated blood. There is also a risk of a transfusion reaction that may cause the red blood cells to break.

Overall, the risk of your baby becoming ill due to a transfusion is very small. You must decide with your doctor if the risks of having a blood transfusion are higher than the risk of not having the transfusion.

Can I refuse?

If you do not want your baby to have a transfusion because of religious beliefs or for some other reason, you must inform your doctor. There are risks to your baby if your baby needs a transfusion and does not get one. Discuss these risks with your doctor.

Can my baby have my blood?

The Canadian Blood Services offers a way for parents to donate blood for their baby.

It is important to know that most studies show that this type of donation (called a *directed donation*) is no safer than blood from healthy volunteer donors. In fact, blood donations from close family are more likely to cause a serious immune reaction. It may also mean that in the future, if your baby ever needs an organ transplant, he or she may not be able to get it from a family member. You need to think about this before you give your baby your own blood.

The only people who can direct their blood for your baby are the baby's:

- parents
- adoptive parents
- legal guardians

The process to do this takes a number of steps. It may take up to 2 weeks for the blood to be ready for your baby. Therefore, this is not an option if your baby needs blood very soon.

Steps to Donate Blood for Your Baby (Directed Donations)

You must meet all the conditions set out by the Canadian Blood Services.

- You must have a physical exam and blood tests at a doctor's office to make sure you are healthy.
- Ask your baby's nurse for the forms that the doctor needs to complete.
- You should have your physical exam done by your own doctor. If you are from out-of-town, you can ask your baby's pediatrician to help arrange this or go to a Walk-in Clinic.
- Along with a check-up, the doctor will also need to take blood samples from you to check your hemoglobin level and to have your blood tested for CMV (cytomegalovirus) infection.
- If you don't know your blood type, this will need to be checked as well. Your blood type must be compatible with your baby's blood.

If you have more questions, call the Canadian Blood Services at 789-1068.

When do things happen in NICU?

Every baby's day is different and depends on his/her needs and condition. In general a day in NICU looks like this:

7:15 a.m. – 8:00 a.m. Nursing shift change. Nurses discuss your baby and his or her care.

9:00 – 11:00 a.m. Patient Rounds. The members of the team go around the unit to each

bed and talk about each baby. They make a plan for the care that day.

You are a part of the team and can be a part of rounds every day.

3:15 p.m. -4:00 p.m. Nursing shift change. Nurses discuss your baby and his or her care.

7:15 p.m. – 8:00 p.m. Nursing shift change. Nurses discuss your baby and his or her care.

8:00 p.m. – 10:00 p.m. Some of the bathing and weighing of babies is done during this time.

You may watch or help the nurse. Baths are not done every day. This is often a good time for you to see your baby awake. Bath time is flexible and you can speak to your baby's nurse if this is not a good

time for you but you would like to be present.

10:00 p.m. – 8:00 a.m. This is when the lights are dimmed and the unit becomes quieter for the night. Although this is not always possible, it is important for the

babies to get quiet sleep. You may be with your baby, but it helps all the babies to sleep if visitors are limited during this time.



Rounds

Who are all these people?

Many people work together to care for babies. You may meet some or all of them. Write their names here if you wish:

The Doctors:
Pediatrician A doctor with extra training in the care of babies and children. This doctor will see your baby in hospital and will be your baby's primary doctor after he or she goes home. This doctor will talk to you about your baby and important test results.
Neonatologist A pediatrician with extra training in the care of sick newborns.
Neonatal Fellow A pediatrician who is getting extra training in newborn intensive care - a future neonatologist.
Resident A doctor who is getting extra training to be a pediatrician or some other specialist.
House Medical Officers A doctor who works only in newborn areas.
The Nurses:
Program Team Manager / Patient Care Manager A nurse who is in charge of all the nurses and many of the other staff.
Staff Nurse The nurse who takes care of your baby.
Clinical Resource Nurse (CRN) A nurse who is in charge of the unit for the shift, who coordinates the day-to-day care in the unit and who helps the staff nurses and others who work in the unit.
Continuing Education Instructor / Nurse Educator A nurse who is responsible for education of nursing staff within the NICU. She is a resource for both nurses and parents.
Clinical Nurse Specialist A nurse with extra education who works on special projects and is a resource for both nurses and parents.
Nurse Practitioner A nurse with extra education and training in the care of sick newborns. She is responsible for overseeing the day-to-day care of some babies in the unit.
Lactation Consultant/Lactation Support Nurse (LC/LSN) A nurse with extra knowledge in helping with breast-feeding.

Other Health Workers

Social Worker
Social Worker A person who will help you with non-medical issues, such as where to stay, getting help at home,
and who provides emotional support.
Dietitian A person with knowledge in the nutrition needs of babies. She helps babies grow with TPN (IV
A person with knowledge in the nutrition needs of babies. She helps babies grow with TPN (IV nutrition), special powders for mom's milk, special formulas, vitamins, and minerals.
Pharmacist
Pharmacist The pharmacist advises the team on medicines for babies.
Respiratory Therapist (RRT)
Respiratory Therapist (RRT) A person with knowledge in the care of breathing problems, who is responsible for equipment
such as breathing machines.
Occupational Therapist (OT) A person with knowledge in baby development and feeding.
A person with knowledge in baby development and feeding.
Physiotherapist (PT)
Physiotherapist (PT) A person with knowledge in assessing and treating baby's lungs and helping treat movement
problems.
Unit Clerk / Nursing Assistant / Ward Clerk
People who answer the phone, help with paper work, send tests to the lab, keep the unit filled
with supplies, and who help the nurses and other staff.
Students
As this is a teaching hospital, your baby may have students involved in care (nursing, RRT, OT, PT, Dietetics). All students work closely with unit staff.
11, Dictales). All students work closery with unit start.

Housekeeping StaffPeople who keep the hospital clean.



"Life Preservers"

What are all these wires and tubes?

The equipment provides the nurses and doctors with information about your baby at all times. These monitors are painless and are attached to your baby's skin. Your baby will have some, but likely not all of them.

Monitor

This is sometimes called a heart monitor. It shows how your baby's heart is beating, and how

your baby is breathing. Three small patches are attached gently to your baby's skin. The patches have wires attached to them. The wires are plugged into the monitor by a cable.

Blood pressure may be measured using a small cuff wrapped around your baby's arm, the same way your blood pressure is measured in the doctor's office. It may also be measured through a tiny tube into one of your baby's arteries. A wire connects the tube to the heart monitor to give a constant readout of the blood pressure. This line can often be used to take blood samples as well.

The oxygen in your baby's blood can also be monitored. A tiny light is attached to your baby's foot or hand with a piece of elastic tape. A cord connects the light to the monitor, which shows the amount of oxygen being carried by the red blood cells.



Temperature Probe

A coated wire will be taped to your baby's skin to measure temperature. This wire is attached to the heater in or over the bed, so that your baby will be kept warm.

Intravenous (IV)



An IV is a small tube placed into one of your baby's veins. It is attached by tubing to a bag or syringe filled with fluid. These contain medicines and nutrients, which your baby needs. The IV pump gives the fluid to your baby at a prescribed rate. Common sites for IVs are hands, feet, arms, legs and scalp. When an IV is in a scalp vein, small areas of your baby's hair may be shaved. The nurses will keep this hair for you if they can. It is common for IV sites to be changed often because baby's vein are small and fragile and often cannot handle an IV for a long time.

Umbilical Artery or Vein Catheter (UAC, UVC)

This is a small tubing threaded into your baby's artery or vein in the belly button (umbilicus). It can be used to give fluids, medicines and nutrients. It is also used to take blood samples.

Incubator / Isolette

An incubator is a bed that provides heat and humidity to your baby. They have a Plexiglas cover to keep the heat and humidity in. There are ports, which open to allow you and the nurses to care for your baby. The side also opens to allow the nurses to change the linen and to take the baby out.



Open Bed

The open bed provides heat from a heater above it. The sides of the



bed can be lowered to make it easier for you to see and touch your baby. Most preterm babies are kept on an open bed for at least a few days after they are born.

Bilirubin Lights

These are fluorescent lights which are attached to an open bed or which are placed over an isolette. These lights give phototherapy that is used to treat jaundice. A bili blanket may also be used to treat your baby for jaundice. Your baby either lies on this blanket of light, or is wrapped in it. Your baby's eyes will be covered by soft eye pads to protect them when the lights are on.

Ventilator

A ventilator is a breathing machine that gives air and oxygen to your baby's lungs through an ET tube (see next page). There are different machines that deliver the air in different ways. The machine can do all or some of the breathing for your baby. As your baby weans from the machine, your baby will do more breathing for him/her self.



Endotracheal Tube (ET Tube)

This is a tube that goes from your baby's mouth or nose into the windpipe (trachea). It is secured with tape and is attached by tubing to a ventilator. It pushes air into your baby's lungs.



Nasal CPAP (Continuous Positive Airway Pressure)

Some babies who do not need a machine to breathe for them but do need a little help to breathe more easily may be given nasal CPAP. Oxygen is given under a small amount of pressure through little tubes that fit into the nostrils of your baby's nose. This helps keep the air sacs in the lungs open so that it is easier for your baby to breathe.



The Family Waiting Area

The Family Waiting area is a half-circled shaped area with glass blocks located near the elevators on the third floor of the hospital. There is a direct-line phone, which connects you to NICU.

Family Rooms

B3003 is a room you can use if you need a quiet place to rest. B3005 is a room you and your other children can use when you are waiting to visit your baby. You need a number code to get in these rooms. Ask your nurse for the code and write it here______. Please do not share the door access code with other visitors—it is for family use only. If you did not get information about these rooms, ask your nurse for an information sheet. There is space in these rooms to leave coats during your nursery visit. You may phone the NICU from these rooms by dialing 2775.

Cafeteria

The hospital cafeteria is on the main floor. It is open from 7:00 am to 7:00 p.m. There are other food vendors located in the Atrium on the main floor

Phones

Pay telephones are across from the main elevators on each floor. Please note **cellular phones are not allowed** in the hospital. These phones *must* be turned off, as they may interfere with equipment in the hospital.

Parking

A parkade is located on Tache Avenue. You can get parking passes at the Parking Office on the Main floor. Parking passes may help reduce the cost of parking at the hospital.

Smoking

Smoking is not allowed at St. Boniface Hospital.

Gift Shop

There is a Gift Shop on the first floor of the hospital near the main entrance.

Pharmacy

There is a pharmacy in the Atrium of the hospital.

Books

NICU has a book called <u>Newborn Intensive Care: What every parent needs to know</u>. Talk to your baby's nurse or social worker to borrow this book.

Libraries

The Family Information Library at Children's Hospital CK204 loans books and videos on many

aspects of child health care. You are welcome to visit the library, even if your baby is not a patient at Children's Hospital. There is a computer there for your use as well. For more information call 787-1012.



Spiritual Care

Spiritual care is available upon request. There is a chapel on the 2nd floor of the hospital. For more information call 237-2356. You are welcome to bring in your own pastor, minister or other spiritual advisor.

Interpreters

French Language Services: 258-1081
Interpreters for other languages: 787-2071

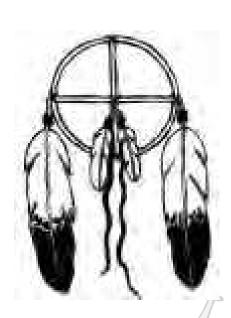
Your nurse can help you access interpreters as needed.

Aboriginal Services

Services are offered to Aboriginal patients by Aboriginal people who:

- Interpret
- Support and teach
- Counsel and refer
- Meet cultural and spiritual needs
- Journey with you

For more information call 237-2306. You are welcome to bring in your own Aboriginal advisors or Traditional Healers.



Information About St. Boniface General Hospital

St. Boniface General Hospital is a work of charity of the sisters of Charity of Montreal "Grey Nuns". We are a teaching hospital with the University of Manitoba. The mission of St. Boniface Hospital is patient care, education, and research. We respect life and the dignity of all people, regardless of age, sex, culture, ethnic and religious background. We work to provide a respectful and caring environment for people in need.

We know that being in the hospital can be a very stressful time for children and families. We would like to help make your stay as pleasant as we can. Feel free to ask any health care team member about things you do not understand. We want you to take part in your child's care.

Family Bill of Rights

St. Boniface General Hospital believes in family-centered care and supports the rights of your child and family. You and your child have the right to:

- Respect and personal dignity
- Care that supports you as a family
- Information you can understand
- Emotional support
- Care that respects your child's growth and development
- Take part in decisions about your child's care

Family Responsibilities

- Tell us how you want to take part in your child's care.
- Tell us if you do not understand something about your child's care.
- Do the things you agreed to do in your child's care plan. If you cannot follow the plan, please tell us.

How can I get help?

If you have concerns about your child's care, we encourage you to talk to:

- Your child's nurse, the nurse in charge, or the Program Team Manager (235-3012)
- Your child's doctor
- Patient Representative
- Social Worker

Thank you for reading this booklet. We hope it helps you to know how we can help you and your family.

We are here to provide the best possible care for your child and for you. Feel free to ask questions as we work together to help your baby get well.

Glossary

abscess: pocket of pus under the skin. It may come after an infection.

alveoli: Small air sacs in the lung

anemia: Having too few red blood cells.

antibiotics: Medicines used to treat some kinds of infection.

apnea: A pause in breathing which lasts more than 20 seconds. The baby's color may become pale or blue, and the baby's heart rate may slow down.

aspirates: Stomach contents that have not been digested. A tube in the stomach may remove them before the next feeding.

bilirubin: A substance produced when the body breaks down red blood cells.

blood pressure (BP) monitor: A machine to measure blood pressure either with a cuff wrapped around the arm, or through a tube into one of the arteries.

bradycardia: Heart rate less than 100 beats per minute.

bronchopulmonary dysplasia (BPD): A chronic lung disease that may occur in babies who have had severe lung disease, or who were very premature.

cerebral spinal fluid (CSF): The fluid around the brain and spinal cord.

chest tube: A tube put into the space around the lung to drain air or fluid that has collected there.

colostrum: The breast milk made in the first few days after birth. It has many cells that protect babies from infections.

CT Scan: a "Computerized Tomography" scan gives a 3D view of the body's organs and structures.

ductus arteriosus: A blood vessel outside the heart that allows most of the blood to bypass the lungs and go to the rest of the body before birth.

echocardiogram: A test that uses sound waves to give a picture of the heart.

endotracheal tube (ET tube): A tube that goes from the mouth or nose into the windpipe (trachea).

full-term baby: a baby born 3 weeks or less before their due date

gavage feeding: Feeding through a small tube placed into the mouth or nose and down to the stomach. Also called tube feeding.

gestational age: The number of completed weeks of pregnancy (since the mother's first day of her last menstrual period).

gram: A unit to measure weight. 454 grams equals one pound.

grunting: An "ugh" sound made by the baby with each breath. It happens when a baby is working too hard to breathe.

heel stick or prick: A tiny puncture of the skin in the baby's heel using a small, sharp instrument. It is done to collect blood for testing.

hematocrit: The percentage of red blood cells in the blood.

hemoglobin: The part of the red blood cell that carries oxygen.

hernia: A bulge of a loop of bowel from the abdomen into an area where it normally would not be.

human milk fortifier (HMF): A powder added to breast milk to meet the special needs of premature infants.

hydrocele: Extra fluid in the scrotal sac (by the testicle) of boys.

hydrocephalus: Too much fluid in the normal fluid spaces of the brain (ventricles).

hyperbilirubinemia: Too much bilirubin in the blood.

incubator: A bed for a sick baby that gives warmth and humidity.

inguinal hernia: A *hernia* in the groin in girls and in the scrotum in boys.

intraventricular hemorrhage (IVH): Bleeding into or around the normal fluid spaces (ventricles) within the brain.

intravenous (IV): A needle or tube placed into a vein and attached to a bag or syringe of fluid.

intubation: An endotracheal (ET) tube put into the baby's windpipe through the mouth.

Isolette: A common term for an incubator, a bed that warms the baby.

jaundice: Yellowing of the skin and eyes due to a build up of *bilirubin* in the blood. Jaundice is treated with special lights which help the baby break down the bilirubin.

laser therapy: A treatment using high energy in a beam of light.

lanugo: Fine, soft, downy hair that is often seen on the back and shoulders of preterm babies.

meningitis: Inflammation of the tissue covering the brain and spinal cord.

monitors: Machines that measure things like the heart beat or the oxygen level.

MRI: <u>Magnetic resonance imaging.</u> MRI machines give pictures of the body's organs and structures.

nasal CPAP: A small amount of air pressure given by a ventilator through little tubes that fit into the baby's nostrils.

nasal flaring: Widening of the baby's nostrils with each breath.

nasal prongs/cannula: A small soft tube placed into the nostrils that gives extra oxygen. **necrotizing enterocolitis (NEC):** An inflammation causing damage to part of the bowel.

open bed: A bed that provides controlled warmth to a baby without needing to use a closed incubator or blankets.

patent ductus arteriosus (PDA): A ductus arteriosus that has remained open after birth.
periventricular leukomalacia (PVL): Softening of the brain near the fluid spaces (ventricles).
phototherapy: Blue or white lights placed over the baby's bed to help break down extra bilirubin in the blood.

pneumonia: An infection in the lung.

pneumothorax: Air trapped inside the chest between the chest wall and the lung, causing the lung to collapse.

Premature formulas: Special formulas designed to meet the needs of premature babies. **premature infant (Preemie):** A baby born more than 3 weeks before the due date

red blood cells: Cells in the blood that pick up oxygen from the lungs and carry it to all the tissues of the body.

respiratory distress syndrome (RDS): A lung disease partly caused by not having enough *surfactant* in the lungs to keep the air sacs (*alveoli*) open to allow air to move in and out.

retractions: Pulling in of the ribs and center of the chest with each breath. They happen when a person is working hard to breathe

retina: The inner lining of the eye.

retinopathy of prematurity (ROP): Abnormal growth of blood vessels in the baby's eye. **rooting:** Head and mouth movements made by a baby searching for a nipple to suck on. The baby makes small quick side-to-side movements of his/her head with an open mouth.

sepsis: infection.

septic work-up: A series of tests looking for germs in the blood, urine, spinal fluid and lungs.

seizures: A brief period of too much nerve activity. The body tenses up, and the baby may twitch or lose consciousness for a few moments.

surfactant: A slippery substance in the lungs which spreads like a film over the air sacs (*alveoli*) to keep them open so that air can move in and out.

temperature probe: A coated wire taped to the baby's skin to measure the temperature. It makes sure the heater keeps the baby warmed at the same temperature all the time.

total parenteral nutrition (TPN): Fluid containing sugar, vitamins, minerals, protein and fat given *IV* to provide the baby with nutrition.

transfusion: Giving fluid such as blood into a vein through an IV.

ultrasound: A test that uses sound waves to make a picture of structures inside the body.umbilical artery or vein catheter: A small tubing placed in the baby's artery or vein in the belly button (umbilicus), used to give fluids, medicines, nutrition, and to take blood samples.

umbilical cord: The cord connecting the baby to the mother's placenta before birth.

umbilical hernia: A hernia in the area of the umbilical cord or belly button.

umbilicus: The belly button.

urinary tract infection (UTI): Infection in the kidney, bladder, or other structures urine passes through.

ventilator: A breathing machine that gives air and oxygen into the baby's lungs.

ventricles: In the brain, they are the normal fluid spaces. In the heart, they are the two lower chambers.

ventricular-peritoneal (VP) shunt: A tube placed into the ventricle of the brain, connected to a tubing that drains excess fluid from the ventricles into the baby's tummy

white blood cells: Cells in the blood that help the body fight infection