Neonatal Intensive Care Unit (NICU)
Parent Booklet

مؤسسة حمد الطبية
Hamad Medical Corporation
HEALTH • EDUCATION • RESEARCH صحة • تعليم • بحوث

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Congratulations on your new baby!

Dear Parents,

Welcome to the **Neonatal Intensive Care Unit (NICU)** at Hamad Medical Corporation. We have a very special mission for treating and nurturing babies born prematurely or with significant medical problems.

Few families are prepared for the birth of an ill or premature baby. We hope to be able to support and help you during your baby stay in our unit. The NICU environment can be a very confusing and stressful. We hope that this booklet will help guide you through your journey with us.

My team and I are focused on providing you and your baby with the best care, and wish you all the best during your stay with us.

Dr. Hilal Alrifai
Medical Director

Introduction

The NICU at HMC Women's Hospital is a busy place most of the time. This atmosphere, along with the equipment, tubes, wires and devices on and around your baby, may make you feel overwhelmed.

"Don't be overwhelmed"

We hope that the following questions and answers might help you understand some of the issues regarding your baby's stay in the NICU.

Why is my baby in the NICU?

Babies are admitted to the NICU for a variety of reasons. The most common reasons why your baby is at the NICU are because he/she:

- is born prematurely
- has difficulties which occurred before, during or after delivery
- has a problem that needs close observation, monitoring, treatment or investigations

My baby is admitted to the NICU. Now what?

Your baby will be placed in an incubator or a bassinet and looked after by a team of professionals. Your baby's primary physician will explain to you the reasons for admission, and the immediate plan of care. Your baby's nurse or the unit secretary will ensure that we have all your correct contact information. On admission, and depending on your baby's condition, we will need to do a variety of tests or procedures and attach certain monitors and machines. This can be very frightening

to you. Your baby's nurse will explain all of these procedures to you. Communication and knowing what's going on are important in dealing with the NICU experience. Your baby's primary physician will communicate with you on a regular basis so that you are fully informed of your baby's medical condition, and feel confident to participate in his or her care. Because of the nature of hospital work, it is best to do this communication during the morning shift (7.00 am - 3.00 pm). If you are unable to be available during these hours, please inform your physician or nurse, so that we can make suitable arrangements.

When can I come to see my baby?

You can come and see your baby as soon as possible after his/her admission.

Parenting your baby might be strange in the NICU, but we strongly encourage the parental presence in the NICU on a daily basis. We also ask that you respect the following guidelines. These guidelines are in place to help protect your baby from infections and to protect his/her and your privacy.

- Nursing hand-over rounds occur at 6.00 am, 2.00 pm and 10.00 pm. They usually last 20-30 minutes. You may be asked to wait in the waiting area while the nurses finish their reports.
- Medical round take place from 9.00 am onwards. You are welcomed to attend medical rounds during the time that your baby's care is discussed. If you wish to be present, please coordinate this with the nurse looking after your baby.
- You and your guests need to wash your hands prior to entry into the unit. You also need to wipe your hands with the special rubbing alcohol before and after handling your baby or any of the equipment surrounding him/her; you also need to put on a special disposable gown if you intend to hold your baby. Please see the section on infection control for more on this subject.

It is normal to feel uncomfortable, but it is important to touch and bond with your baby from the first day of life. This will make you and your baby less stressed, and is an important step towards your baby's recovery.

Can anyone else visit my baby?

Because of limited space, we ask that there be only two people at your baby's bedside. One of these must be a parent. After admission you will be given a set of visitor cards specific to you. We will admit only people bearing these cards. Please note that information will only be given to the parents. As babies in the NICU are very vulnerable to infections, please ensure that you and your guests are free from colds, and other contagious infections. If you are unsure, please call and check with your baby's nurse before coming to the hospital.

Babies and Infections

Why all this concern about infection?

Babies, and particularly babies who are born early, are very prone to infections because they have minimal natural immunity for the most common germs that are around us. The body's natural defence against infections is not well developed in babies to protect them from infections. Thus, germs that do no harm to you can be very harmful to your baby. In addition, ill or premature babies can get serious infections because many of the necessary procedures we do "break" the skin, such as when we start intravenous fluids, or get blood for lab work. Despite all our precautions, your baby remains at high risk for infections because of this low immunity.

Your baby's healthcare team are constantly monitoring your baby for signs of infections. These signs can be varied and can include:

- Being less active and less alert than usual.
- Having more breath holding (apnoea) episodes than usual.
- Developing new or worsening breathing problems.
- Developing temperature instability even in a warm incubator.
- Not tolerating feeds, vomiting or having increased abdominal girth.
- Showing changes in skin color.

When your baby shows signs indicating the presence of an infection, your baby's nurse will inform the physician looking after your baby. The physician will examine your baby and if infection is suspected, a special blood test will be ordered. This special blood test is calleda complete blood count. At times a urine culture and a spinal fluid culture may need to be collected as well. Your baby will also be taking antibiotics. Depending on what the cultures and blood work show, the antibiotics will be continued or stopped. Your baby's physician and nurse will inform you of the length of time the antibiotics will be used.

So infection can be a serious problem?

Yes, infections can be very dangerous to premature babies. That is why we must all work together to decrease the chances of your baby having a serious infection.

Is there anything that can be done to reduce this hazard?

Infections are caused by germs that can be spread in many different ways. Germs can move through air and they can be found in water. Most commonly, they move from one place or person to another through physical contact. This means it is usually spread through our hands. Thus, the first defence against infection is hand washing and sanitizing. Yet, germs can be found under rings, watches, finger nails, etc. That is why all hand jewelry and watches need to be removed before washing hands. Remember, hand washing needs to be thorough and long enough to be effective. You will notice posters at the entrance sinks explaining and illustrating the technique of hand washing. To know how long to wash your hands for, sing the tune of "Happy Birthday" silently to yourself two times!

Once you washed your hands, be aware of where you put your hands. For example, if you touch your hair, your mouth or your nose, you will need to wash your hands all over again. Remember to use the alcohol hand rub immediately before and after touching your bbay or any of the equipment surrounding your baby.

If you see any of the staff approaching to handle your baby, please feel free to ask if they have washed their hands. We all have to monitor each other to reduce the risk of infection.

If you have a cold or a rash or think you have been exposed to some infectious agent, such as Chicken Pox, it is best not to visit your baby. Just call the unit and inform the charge nurse or your baby's nurse.

What about other visitors like my children?

The same rules apply to your visitors. It would be appreciated if you can inform your visitors about the hand washing rules, and the need not to visit if they have any signs of a cold, a rash or any other infection. Children more than 6 years old can visit, but you need to inform the charge nurse and you have her clearance for visiting.

If you have any questions or concerns or are unsure whether to come into the NICU or not because of an infection, please speak with the charge nurse or your baby's physician before visiting.

Hand washing guidelines

- Remove jewelry.
- Wet hands and wrist area.
- Pump a squirt of soap from the wall dispenser.
- Wash hands and between fingers with firm circular motions.
- If you can, wash wrist and arm up to elbows in similar fashion.
- Dry hands and wrists with a paper towel, going from fingertips to elbows.
- If in doubt, check the instructions found at the sink.

The Neonatal Healthcare Team

I see so many people in the NICU. Who are they?

In the NICU, you will meet many people who look after your baby. All of these people are committed to providing the best care for your baby, and will be giving you information based on their involvement with him/her. Occasionally, it may be necessary to set up a special meeting so that all those involved in the care of your baby can meet together with you, so that your baby's care is not fragmented.

To help you understand who is who in the NICU, here is a brief list of the main people you will meet:

- **Consultant**
  A senior doctor who has specialised training in the care of ill or premature babies. They coordinate and determine the care of the babies in the NICU. Consultants work with a team of specialists and pediatricians in training. They rotate throughout the year, so you may meet more than one consultant during your baby's stay in the unit. Feel free to ask your baby's nurse if you would like to speak with your baby's consultant.
- **Specialist**
  A doctor who is specialised in the care of sick children and works under the supervision of the consultant. The specialist will examine, order care and write notes regarding your baby.
- **Clinical Nurse Specialist/Nurse Practitioner**
  A senior nurse who has additional education and training specific to the care of ill babies. She will coordinate the nursing care and provide some aspects of medical care to your babies, in partnership with the consultant.
- **Head Nurse**
  A senior nurse who coordinates the health care team and oversees all aspects of the NICU management.
- **Case Manager**
  A senior nurse who will ensures that your baby's stay and discharge from hospital is efficient and well coordinated.

The doctors and nurses provide continuous 24 hour care to your baby

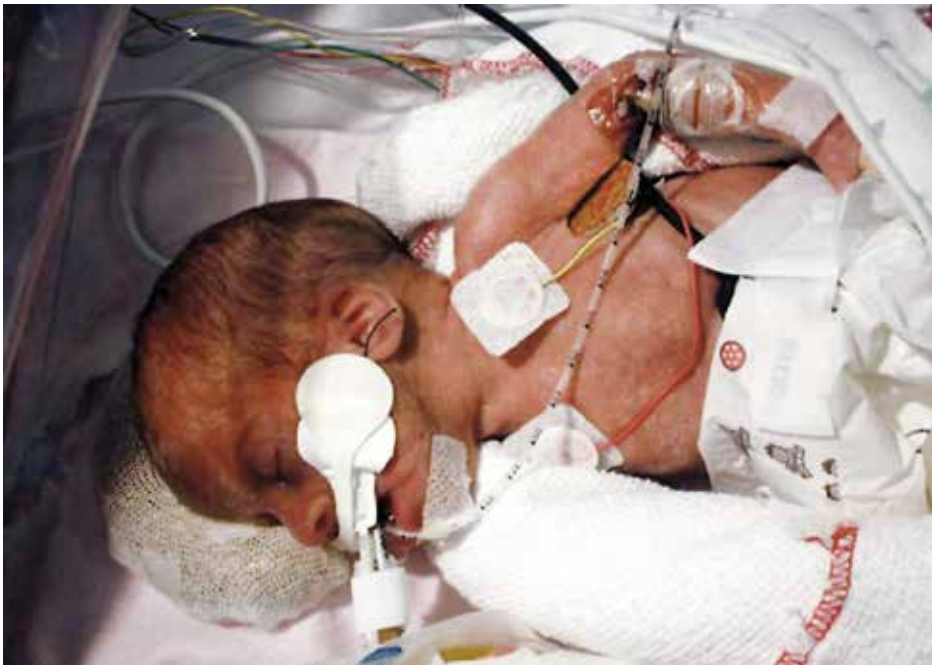
- **Charge Nurse**
  An experienced nurse who coordinates the day to day activities of the NICU to ensure the smooth running of the unit.
- **Staff Nurse**
  A nurse who has experience and training in the care of ill babies. She continuously monitors your baby and is the eyes and ears of the doctors. She will be your primary source of contact in the unit, and a valuable advocate for your baby.
- **Respiratory Therapist**
  The respiratory therapist works in collaboration with the physicians and the neonatal nurse, to help your baby breathe more easily. The therapist operates a wide variety of equipment, including breathing machines, oxygen and other special devices to assist babies with breathing problems.
- **Occupational Therapist**
  A person who is specialised in the baby's development. She will usually work with you to help your baby achieve desired milestones.
- **Physiotherapist**
  A person who is specialised in ensuring that your baby achieves his potential in functional activities.
- **Social Worker**
  A professional who has special training in providing support/resources to meet the psychosocial, emotional and financial needs of families.
- **Pharmacist**
  A professional with specialised education and training in the preparation and use of medications that will be used in the NICU. They can also provide information on the use of medication that your baby might be discharged home with.
- **X-ray Technician**
  A professional who is trained to take x-rays of your baby.
  In addition to the above, your baby might need consultation with specialist from other departments. Your baby's primary physician and nurse will inform you if your baby needs such a referral.

Prematurity

What is Premature Birth?

It is a birth that is at least three weeks before a baby's due date. It is also known as pre-term birth (or less than 37 weeks-full term is 40 weeks of gestation). Important growth and development occurs throughout pregnancy – all the way through the final months and weeks. Although most babies born a few weeks early do well with no health consequences, some have more health problems than full-term babies. For example, a baby born younger than 35 weeks of gestation is more likely to have:

- Breathing problems
- Feeding problems
- Infections
- Longer hospital stays



Most pre-term deliveries happen spontaneously and without a known cause. Doctors sometimes decide to deliver a baby early because of concerns for the health of the mother or the baby. Medical intervention for an early delivery should only be considered when there is a medical reason to do so.

The more pre-term a baby is born, the more severe his or her health problems are likely to be. Although babies born very pre-term are a small percent of all births, pre-term delivery is the most frequent cause of infant deaths. Some premature babies require special care and spend weeks or months hospitalized in the Neonatal Intensive Care Unit (NICU).

In addition to specific diagnoses, babies in the NICU can experience general problems. For instance, babies lose heat easily, and premature babies in particular have trouble regulating their body temperature, as they lack the energy or fat reserves to generate heat and the body mass to maintain it. Hence NICU babies must be kept warm in warmers or incubators.
High or low blood pressure can also be a risk for premature babies. This can lead to bleeding in areas of the brain because their developing blood vessels can't handle changes in blood pressure and may tear more easily.
Some premature babies have trouble feeding because they are not physically coordinated enough yet to do it. Eating is the most energy-consuming process for a newborn, and babies in the NICU often don't have the strength or energy to feed on their own. Instead, they have to be fed through a small line inserted into a blood vessel or a tube into the babies stomach. . If the digestive tract isn't sufficiently developed to handle food, that can also cause specific problems too.

A related condition is reflux. Reflux occurs when the muscle that controls the opening of the esophagus and the stomach is weak. This allows the acidic stomach contents to bubble back up into the esophagus. The acid irritates the esophagus, which can lead to feeding problems. Inhaling and choking on the reflux is a more serious risk.

Babies that need intensive care are also vulnerable to infections. Premature infants have low immunity, and in the NICU, when babies are close together, infections can spread easily. Another way infection spreads is through the care givers' hands. That's why NICU staffs are vigilant about hand washing and keeping that environment as clean as possible.

Developmental Care

Your premature baby may have certain features that differ from those of a full-term baby.
You will notice that the head and face of a premature baby tends to look long and out of proportion with the rest of the baby's body. He/she will look thin and small with little body fat and skin that looks smooth and very fragile. He/she will lie with arms and legs outstretched due to lack of muscle tone. Sometimes if the baby is born very prematurely, the eyelids are still closed and not yet open.
When your baby is born prematurely, he/she leaves the security of the womb, for life in the NICU. The NICU can be a busy, noisy and crowded place, quite different from the environment of the womb. We try to do our best to recreate that environment through different ways such as minimizing the noise and traffic even though at times it can be unavoidable. You will also notice that the babies' incubators are covered with blankets, and that each baby sleeps in the incubator, surrounded by rolls of blankets. These strategies are meant to provide the darkness, and the feel of the womb.

We believe that too much disturbance is not good for your baby. That is why babies are only handled at certain times, and only if there is a need for it. Your baby can and will show signs when he/she is ready to interact, or when he/she is stressed, and needs to be left alone. Your baby's nurse will help you understand these signs. Your baby's nurse will also show you the best way to touch and interact with your baby.

Being born early, your baby's ears are not used to loud noises, and are quite sensitive to it. For that reason, you will notice that your premature baby has his/her ears covered by yellow ear muffs. You, as well as your baby's nurse can advocate for your baby by reminding those around the incubator to speak in soft voices and hold conversations at a distance.

While developing inside your womb, your baby was used to your smell and your voice. You can help your baby adjust to the NICU environment and reduce his/her stress by regularly visiting, touching and holding your baby. The feel of your skin next to your baby's skin is very beneficial. This can be achieved by holding the baby either inside the incubator, or outside the incubator when he/she is more stable. This is called skin to skin or kangaroo care. You might be hesitant to do this initially, but with your baby's nurse's help, you and your baby will enjoy the experience. We encourage you to do this as often as you can.

What is your baby saying?

I'm ready to listen and interact

Stop... I'm tired now and no longer interested

This is how you can calm me down. I like firm pressure on my head and buttocks. I do not like stroking...

Your Baby's Nutrition

Will my baby be able to eat right away? If not, how will he get his nutrition?

A premature baby may not be ready to eat right away. Depending on his/her clinical condition, we will withhold feeds until your baby is more stable, and till the physician looking after the baby thinks he/she is ready to eat. If it will be a long time till your baby's nutritional needs are met by milk, he/she will get his nutrition through an intravenous catheter, and receive what is known as Total Parenteral Nutrition (TPN). This is a solution of sugar, vitamins, minerals, proteins and fats. You will know if you baby is receiving TPN if one of his IV solutions is covered in foil, and another has a white color. The physician will vary the composition of this TPN depending on your baby's nutritional needs.

I see a tube in my baby's mouth/nose. What is that?

The tube that you see in your baby's mouth is called an orogastric tube (OGT). At times it is also inserted through the baby's nose, and then it is called a nasogastric tube (NGT). This is a soft thin catheter that goes straight to baby's stomach. It can be used to give milk to the baby when he/she is unable or not ready to suck, or remove unwanted fluids from the stomach if your baby is not being fed. The tube will not bother your baby.

What is my role in my baby's nutrition? He is so small and does not even know how to suck!

We strongly advocate the use of breast milk in the NICU. Even if you are not planning to breast feed your baby, we strongly advise you to pump that first week of life, and have breast milk available for your baby when he/she is ready to be fed. It is one of the most important things that you can do as a mother and something that only you can do. If for whatever reason you are unable to pump/have breast milk, we have special premature formulas that we can give to your baby.

Your baby might be too small to suck, but that does not mean he cannot be fed. When the doctor thinks your baby is ready to be fed, we give small amounts of feeds through that tube in your baby's mouth. The amount of this feed is gradually increased according to a special schedule, as long as your baby is able to tolerate it. When your baby is bigger and stronger, and is tolerating all his/her feeds by OGT/NGT, and if you want to breast feed, you can coordinate with your baby's nurse to start placing the baby on your breast. This usually needs enough maturity to be able to coordinate sucking, swallowing and breathing, and usually occurs between 33-35 weeks of gestation.

How does the nurse know that the baby is tolerating his/her feeds?

Your baby's nurse keeps a close eye on your baby and monitors various signs that can indicate whether or not your baby is tolerating feeds. She will pull back with a syringe the OGT/NGT and check if there is leftover milk from the previous feed. Usually the milk should have been digested, and so there is minimal milk pulled back. If there is too much milk pulled back, the nurse will notify the physician who will examine the baby thoroughly and decide to continue or to stop the feeds. She will do the same if she notices that the baby's tummy is looking rounder, and fuller than usual. The physician may also order an x-ray to get a better understanding of what's going on.

How can I make sure I have enough milk for my baby?

You will start producing milk as soon as your baby is born. Initially this may not look like milk, and may be in very small quantities. We want to assure you that is perfectly normal, and that this "milk" is very beneficial to your baby. Thus ask your nurse to arrange a breast pump for you as soon as you can after delivery, so that you can start pumping right away. This will get you off to a great start. If you intend to breast feed your baby, we encourage you to pump 8 to 12 times a day round the clock. You must also remember to take care of yourself. Proper nutrition, hydration and rest are important if you want to keep up your breast milk supply.

Another excellent way to ensure good supply is to visit and take part in your baby's care as often as possible. We also strongly advocate "kangaroo caring" for your baby as soon as your baby is medically ready for it. Please speak to your baby's nurse for further information and try to attend the Thursday education sessions that are arranged weekly in the unit.

How do I pump my breast?

To achieve a good milk supply, use an electric pump. We have electric pumps that you can use while in the hospital. You can also look into buying one for home use. Below are the steps to follow:

- Wash your hands with soap and water or usehand sanitizer
- Clean your breast with water and dry well
- Gentle massage your breast in a circular or rolling motion towards the nipple of each breast before pumping.
- Center the clean breast shield over nipple and ensure it is fitted correctly.
- Begin pumping on the minimum suction setting and then increase the pressure as tolerated. If your nipple hurts, put off the pump and gently remove the cup, reposition the pump correctly.
- Pump each breast for 15-20 minutes until your milk stops dripping and your breast is completely empty. Then switch to the other breast.
- You can pump at two to three hour intervals so that you can have 8-12 pumping sessions a day. The less you pump, the less you will produce. Thus the trick to a good supply is to pump regularly morning, noon and night.
- Use a pillow behind your back for support when you pump.
- Have a drink close by, as pumping may make you thirsty. To help with milk "let down" look at pictures of your baby or think about him/her.
- Use a new container each time you pump. Do not pour milk from one session of pumping on top of previously pumped milk.
- Label each container with the name sticker as well as the date and time of pumping

- If pumping in the hospital hand your milk to your baby's nurse. If pumping at home, freeze you milk right away.

Freezer of a 2 door Fridge: 2-3 months

Fridge: 3 days

Deep Freezer: 6 months (-18°C)

How long can I store my milk?

Expressed breast milk (EBM) can be stored according to the table below:

Freshly pumped EBM at room temperature	4 hours
Freshly pumped EBM placed in the fridge (fridge temp = 50° to 10°)	2 days
EBM placed in the freezer compartment of the fridge	3 months (make sure the milk is stored towards the back
EBM placed in a stand alone freezer	6 months (make sure the milk is stored towards the back or bottom of freezer)

How do I transport my EBM?

Transport EBM as per chart below:

Freshly pumped EBM	Transport in a cooler
Solid frozen EBM taken from the freezer	Place each container of frozen EBM in a zip lock bag, and transport in a cooler packed with ice or special ice packs
Partially thawed milk (slushy EBM)	In cooler with ice

Remember the storage times apply and should be included to the transport times.

How do I thaw my milk?

Thaw the oldest frozen milk first. Place the frozen container in the refrigerator the night before you intend to use it. You can also gently warm the desirable amount of milk by placing it under cool then warm running water or in a bowl of warm water. The remaining thawed milk can be kept in the fridge and use within 24 hours.

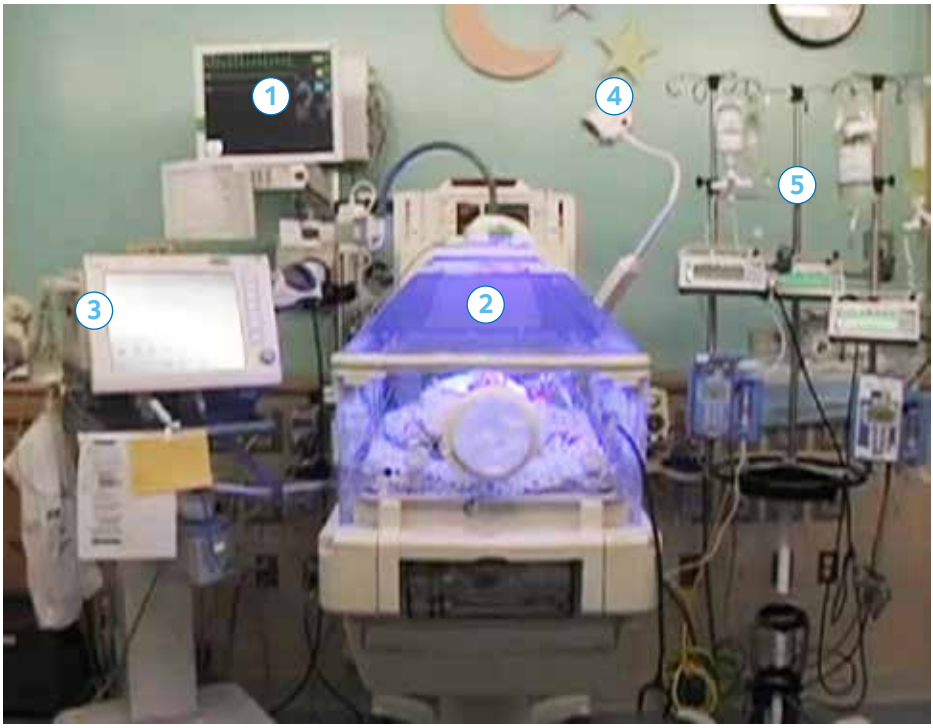
Do not freeze the remaining thawed milk.

Your Baby and Technology

What are all these devices attached to your baby?

As you can see from the picture below, we use a lot of technology In order to provide the best of care to your baby. Here is an explanation of the most commonly used equipment in the NICU,

1. **Cardio Respiratory Monitor:** This devices monitors your baby's heart rate, breathing, and blood pressure and oxygen/carbon-dioxide levels. You will see these values displayed on the screen. The devices does this by wires that are connected to your baby's chest, abdomen and limbs.
2. **Incubator:** This is your baby's "bed". In this bed, temperature, humidity and other factors are tightly controlled. Your baby will stay in this type of bed till he/she is big enough to be able to be in an open cot.



3. **Ventilators:** These are breathing devices that either assists or takes over breathing for your baby until such time that your baby is able to breathe effectively on his/her own. The ventilator has many controls that get adjusted depending on your baby's clinical condition and results of blood test that is called blood gases.
4. **Phototherapy:** This is a blue light that is used in conditions such as when your baby has jaundice. The term jaundice is used when there is a yellow discoloration to your baby's skin. When your baby is placed under phototherapy lights, his/her eyes will be kept covered with a special mask. We will also use minimal clothing and a very small diaper so as to expose the maximum area of skin to the light.
5. **Intravenous pumps:** These are devices connected to your baby's IV catheter and used to deliver fluids and nourishment to your baby in precise volumes and rates.

You might notice many other devices being used for your baby. Your baby's nurse will give an explanation as to their use. However, if you see equipment being used which you are not familiar with, please feel free to ask your nurse.

Things you can do for your baby

- Visit often and get to know your baby.
- Read to your baby.
- Talk to your baby in a soft and gentle voice.
- Keep a diary or scrapbook for your baby (you can ask your nurse if one is available).
- Arrange to do "kangaroo care" with your baby.
- Participate as much as possible in your baby's care.
- Be patient. Your baby needs time to get better.
- Get to know the people who are caring for your baby.
- Educate and inform yourself about your baby's condition and plan of care. You are part of your baby's health care team.
- Feel free to bring in your own linen for the baby. Just be aware that you will be responsible for the laundry of the linen you bring in. Also, label any clothing, toys, books, and other belongings that you leave with your baby.
- Attend the weekly educational classes.

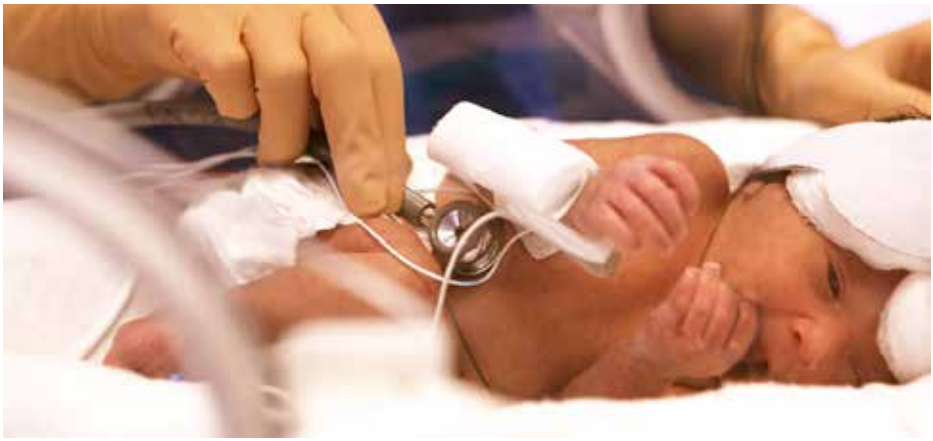
The NICU Emotional Roller Coaster

Coping with your Emotions and Feelings

Having a baby in the **Neonatal Intensive Care Unit (NICU)** is extremely difficult. Parents may not get that same bonding time in the first few hours and days of their baby's life. If you aren't staying near the hospital where your baby is being cared for, you're looking at daily commutes back and forth to the NICU, going home each time with empty arms.

All of our NICU staff understand the difficulties parents may face with having a baby admitted to the NICU. Doctors, nurses, and social workers are available at all times to discuss your concerns and feelings. Regardless of the severity of your baby's diagnosis, having a baby in the NICU is a rough road. It is important to understand that some parents will experience a **"roller coaster"** of emotions and tensions while their baby is admitted. However, they are not alone because there are other parents and staff members that can help them through their difficult situation.

It's natural to feel anxious about all the people responsible for the health and care of your baby. But be assured - the staff in the NICU are exactly the people you want caring for your child right now. They each have a specialized job to do, and they work as a team to provide complete care to your baby. And, of course, **YOU** are at the center of this team. In time, you may all begin to feel like part of an extended family.



Here are a few tips to surviving your baby's days in the NICU, from a parent who had her twins in intensive care for a total of three weeks.

- It sometimes helps to acknowledge and share your feelings with family, friends, your doctor and other professionals. Seek out and use the support and resources offered at Women's Hospital, Hamad Medical Corporation.
- Case managers and social workers are available to help you deal with you and your family's emotional strains. If necessary, they will assist you in seeking more professional help.
- Attend parent education classes organized by the unit. Ask your baby's nurse to find out when and where these classes are held.
- Take care of small tasks: At times when your baby is sleeping and you cannot have direct interaction with him/her, help pass the time by doing small tasks. Bring reading material, keep in touch with friends through mobile technology, pay bills etc.
- Don't call everyone every day: Don't feel obliged to call every member of your family every day with a status report, particularly if news isn't good or remains unchanged. Perhaps you could designate one person whom you'll call and that person could spread the word to other interested parties. Or, if friends and family have Internet access, you or your spouse could send a daily e-mail update. But if keeping everyone updated is upsetting you such as when some folks make inappropriate comments such as, "What, he didn't eat again today? He doesn't sound like he's improving." It is better to tell everyone you'll call when you can, or just have a spouse contact people.

Take help from others: In situations like these, people often offer to help. Take up their offers. Driving back and forth from the hospital, picking up children from school, baby sitting children, cooking warm meals are all chores that family and friends can help with, freeing you to be with your baby as much as possible.

Parent Information Classes

The NICU staff conducts parent information classes every week. These classes take place in the NICU conference room. We call these days **"HUG"** days which stands for **"helping you grasp"** all the details regarding your baby's care while in the NICU and, ultimately, at home.

We invite you to come and actively participate in these classes. We cover many topics such as orientation to the NICU, general issues of prematurity, how to survive the NICU roller caster, tips on breastfeeding, discharge planning, positioning and handling, and social networking opportunities.

The classes are conducted by our social workers, case manager, clinical nurse specialist, physiotherapists and occupational therapist. The topics and timings for each week are posted on the bulletin board in the waiting area of the NICU as well as inside the NICU.

We encourage you to attend these classes as often as you can. Not only will it give you an opportunity to be informed and confident in your baby's care, it will also allow you to meet other mothers in similar situations, and partake in some refreshments as well.

See you there soon!

Homecoming

Finally, you hear the words, "Your baby is going home."

For the last few months, you have been coping with your baby's prematurity, medical problems and hospitalization, so it may be difficult to imagine that your baby will ever be healthy enough to come home.

However you can anticipate that the time is getting near for taking your baby home:

- When your baby is stable and has no issues with his/her breathing and heart rate.
- Is able to maintain his/her temperature outside the incubator (in a crib).
- Is feeding well by bottle or breast.
- Is gaining weight.
- Has no **active** medical issues.
- Parents are well trained to look after their baby.

It is common for parents to experience anxiety about taking care of their baby at home, after she/he has been dependent on medical and nursing care for some time.

You may feel:

- The excitement of your baby coming home is overshadowed by the fear and anxiety of looking after your baby.
- Unsure about your ability to provide for your baby as well or to recognize and manage any health problems that may occur.
- Worried that your baby may get ill and have to be re-admitted into the hospital.
- Concerned about feeding. You may have experienced difficulties with breastfeeding or bottle-feeding as your baby may be a "slow" or "fussy" feeder and this may contribute to a sense of frustration, worry, discouragement or even a feeling of failure.

Therefore, it is important for you to participate in your baby's care now in order to prepare for discharge!

In the following pages you will find information regarding some aspects of your baby's care at home. We hope you find it useful.

Preparation for Homecoming

Before your baby goes home here are some things that you need to consider:

- Painting and decorating of the baby's room (if needed) should be done as early as possible.
- Purchasing a car-seat, crib, clothing, diapers and bottles are all things that can be done early on and are best not left to the "last minute".

What do I need to buy?

Baby Supplies:

- Diapers
- Diaper shirt (under vest), sleepers, nightgowns, socks, hat, sweaters
- Receiving blanket, blanket, crib sheets
- Outdoor clothing (depends on the season)
- Bottles, formula

Baby Equipment:

- **Crib:** The mattress must fit properly so there are no gaps between the mattress and the crib. The paint on the crib must be lead free. It is not necessary to buy a cradle or bassinet.
- **Car Seat:** Please arrange with your nurse to have a car seat demonstration prior to discharge.
- **Stroller:** When purchasing a stroller, you may want to take into consideration the size of wheels, how it folds and its storage, size of basket, how good the reclining seat is, how easy it is to fasten restraining straps, etc.

Other Suggestions:

- **Playpen:** This is the safest place to put your baby, it also encourages safe "floor play" which promotes normal development.
- **Baby Swing:** Great way to calm an unhappy baby. Never leave your baby unattended, until he/she has good head control.
- **Baby Carrier:** Babies love to be carried. There are different kinds that you can buy; the "sling" and front carrier that support your baby well are recommended. Read the instructions to check when you can put your baby into a carrier.

Car Seat Safety

All babies must be secured in a safe car seat every time they ride in a vehicle. One of the most important jobs you have as a parent is keeping your child safe when riding in a vehicle. Each year thousands of young children are killed or injured in car crashes. Proper use of car seats helps keep children safe.

Prior to purchasing a car seat, you need to know your baby's weight and height, as there are different car seats for each weight category. Your newborn baby needs a rear-facing car seat until he or she is at least 1 year old and 22 pounds (10 kg). The best place to put the rear facing seat is in the back seat of the vehicle. Rear-facing restraint systems must never be placed in the front passenger seat of any vehicle equipped with a front passenger side air bag.

Before putting your child in a car seat, read both the car seat manufacturer's instructions and your car's manual so you know how your car seat works and how to fix it properly in your car.

Some rear facing car seats come with a base that can be left in the car. The seat clicks into and out of the base so you don't have to install the seat each time you use it. Install this base following the manufacturer's recommendation and ensure that it is secure. If you can move the seat at the belt path more than an inch, side to side or front to back, it's not tight enough.

Steps in placing your child in the car seat:

- Ensure that the car seat that you buy has a 5 point harness. This means that a strap comes over each shoulder, across both hips, and has one strap between the legs. All 5 parts of the harness come together at a common buckle. 5-point harnesses are considered to be the most protective type of harness.
- Thread the harness straps through the slots located at the back of the car seat so that they are at or below your child's shoulders.
- Place your child in the car seat with the child's back flat against the car seat.
- Place the harness straps over the child's shoulders. Harness straps should lie flat, not twisted. You should not be able to fit more than one finger underneath the harness straps at the child's collarbone.
- Buckle the harness, and the chest clip. The chest clip should be flat against the chest at armpit level. Tighten the harness until snug. Bulky clothing or blankets can prevent a snug harness fit. Always buckle the baby in the seat first, and then place coats or blankets over the harness.
- If your baby needs support, fill the empty spaces with small, rolled blankets on each side of the baby's shoulders and head.
- If there is a gap between the buckle and your child's groin (common for young infants), try placing a rolled washcloth or diaper in the space for a more secure fit.
- Do not add anything else to the car seat that did not originally come with the car seat such as head huggers or mobiles.

Important points to remember:

- Never leave your baby alone in a vehicle.
- If possible, have an adult sit in the back seat to watch your baby.
- Use the car seat for travel only. After the car ride, take your baby out of the car seat, even if he or she is sleeping.
- Limit the time your baby spends in the car seat.
  If you make a long trip, take a break every couple of hours and take your baby out of the car seat.

Bathing Your Baby

Each baby reacts differently to bathing. Although you do not need to bathe your baby daily, you may find this activity soothing for you and your baby. Allow sufficient time for baby to recover from the bath before attempting other activities such as breast or bottle feeding.

Bath your baby in an area of the house that is free from drafts. The bathroom or the kitchen may be good choices. Where you bathe your baby must be stable and at a comfortable height. Before starting, have ready all that you need for the bath such as:

- A baby bathtub or basin
- A towel to place your baby on
- A soft terry towel preferably with a hood in one corner, and 2 washcloths to use for bathing
- Cotton balls/diaper wipes
- Mild baby cleaning product and baby shampoo
- A clean diaper
- Clean clothes and blanket

Bathing procedure:

- Fill the bathtub with clean warm water. Test it with your elbow. It should feel warm.
- Place a towel on the work surface. Place the hooded terry towel on top.
- Lay your baby on top clothed in a shirt and diapers. Bundle baby in the hooded terry towel.
- Hold baby in a "football" hold to the side of your body. Wet one cotton ball or the side of one washcloth, and gently wipe one eyelid going from the nose side towards the ear. Discard the cotton.
- Wet another cotton ball or the opposite side of the washcloth and clean the other eyelid in the same manner. Discard cotton ball.
- Wet another washcloth and clean baby's face gently as well as the outer folds and behind the ears.
- Wet baby's head with some water. Use a small amount of shampoo and massage it using your hand or the washcloth. Rinse and pat thoroughly dry with the towel. Cover or place the towel hood on baby's head.
- Lay baby on the work surface on top of the towel. Remove shirt, and diaper and re-bundle loosely.
- Wet and lather hands or the washcloth. Gently clean baby starting from the creases of the neck down to the legs. Turn baby on tummy and repeat the process on the back. Clean the diaper area using a washcloth or diaper wipes.
- Remove baby from the towel, and grasping from behind the neck and the legs, place baby in tub keeping head well elevated above level of water. Rinse baby with cupfuls or splashes of water.
- Remove baby onto the towel, and pat dry thoroughly. Place clean diaper and clothes on and bundle in a blanket.

Please remember the following:

- Always check the temperature of the water.
- Never leave your baby alone at any time during the bath
- Do not forget to wash and dry under your baby's chin and in the folds of the neck.
- Oils, lotions and powder are not recommended for use on your baby.
- It may help to pick a quiet part of your baby's day to do the bath.

Feeding Your Baby

Most parents are quite anxious regarding feeding their baby. We encourage you to be present for all feeds 24-48 hours prior to discharge to become comfortable in this skill.

Below are some questions and answers that you may have regarding feeds.

How often should I feed my baby?

Most babies will feed on demand or without restriction. Small premature babies may not cry when they are hungry, but show other signs such as fussing or restlessness. You are encouraged to wake your baby up if he/she has not been feed for 4- 5 hours.

How much should I feed my baby?

The amount of milk a baby drinks depends on his/her age. A newborn stomach is very small and not ready to digest a large volume of milk. Therefore, your baby's intake will not increase very much after their first month, even though his/her weight continues to increase.

When you spend time with your baby while in hospital, you will get to know how much your baby feeds. A good way to know that your baby is getting enough milk by listening to your babies sucking. You should hear rapid suckling at the beginning of the feed followed by a slow steady sucking and pauses in between feeds. Your babies urine output should be clear or light yellow and you should be changing one to two diapers on the first day to five to six by the third day. If your baby starts to finish feeds quicker, or is still acting hungry after finishing a feed, it may be that you need to increase his/her feeds. If you are breast feeding, baby will suck longer or wake up quicker to take in enough milk. Signs that your baby is not getting enough milk is when your baby has dry mouth and lips, the soft spot on the head feels depressed, and when your baby has only have a few wet diapers a day.

Are there feeding cues that may tell me my baby is hungry?

When your baby is in his/her early hunger stages, you may notice his/her mouth opening. He or she may also turn their head and you may see him/her seeking and rooting. When your baby becomes more hungry, you may notice them stretching and increased movements like putting his/her hand to their mouth. And when your baby is very hungry, he/she will cry, turn red and display agitated movements

How long should a feed last?

The length of each feeding session can vary depending on the baby's age, hunger level and individual nursing style. Generally speaking newborns will feed anywhere between 5 – 40 minutes. If you are breastfeeding your baby, 20 – 30 minutes per breast of good attachment and sucking is usually enough. Your breast should feel softer at the end of the feed. Your baby is full when his/her sucking slows down or stops, you no longer hear a swallowing sound, their arms and hands relax and let go of the breast without attempting to latch on again. If being bottle-fed, your baby should finish the milk in 20 – 25 minutes.

What is burping?

Baby might have swallowed air while sucking. Burping is when baby brings up this air in the form of a belch. In the middle of a feed, or when baby slows down, remove bottle or breast from mouth. Prop baby on your chest or shoulder, and gently tap or rub baby's back till the air comes out. Sometimes baby might bring up a bit of milk with the air. This is a common occurrence and not a cause for worry.

Do I need to give extra fluids to my baby?

Extra fluids in the form of water may fill baby's tummy and do not provide any nutrition. If your breast milk supply is diminishing, you may offer a bottle after a breast feed.

Do breast fed and bottle fed babies stool differently?

Breast fed babies pass frequent stools that are yellow and not very formed. Bottle fed babies pass less frequent stools that may be yellowish brown in color and the consistency of cottage cheese. Each baby has a stooling pattern unique to them. If this pattern changes suddenly consult your doctor.

Sleeping

One of the most important things you can do to help reduce the risk of Sudden Infant Death Syndrome is to put your baby on his or her back to sleep. Do this when your baby is being put down for a nap or to bed for the night. Some babies at first don't like sleeping on their back, but most get used to it and this is the best position for your baby. If your baby needs a special sleeping position for medical reasons, then you will be instructed in this prior to the discharge.

It is important not to put your baby to sleep in the same bed with you or with other children. If you want to sleep near your baby, then put baby to sleep in crib next to your bed. Use a crib with a firm mattress and a tightly fitted sheet. Do not use pillows, bumper pads around the crib, duvets, or thick blankets as these all can cause suffocation. Place baby towards the foot of the bed, dressed in a pajama and if needed, a blanket tucked under the mattress leaving the baby's arms free. Avoid bundling your baby and avoid smoking near your baby. See picture below for the best sleeping position.

As the NICU environment is so much different than your home environment, your baby might find it initially difficult to adjust. Here is what you can do to help your baby's sleep.

- Keep a soft light on in your baby's room.
- Play some soft music, or keep a softly playing radio on. As your baby adjusts, gradually turn the volume of the music or radio down until it is no longer required.
- Establish a routine for naps and bedtimes
- Keep night feeding as unexciting as possible. (Resist the urge to play or interact with your baby).

At first, your baby will feed every 3-4 hours. As baby grows bigger and older, he/she will feed on what is known as a demand schedule: You will feed him whenever he is hungry and crying for a feed, without a set interval between feeds.

If you are unable to rouse your baby for a feed, please seek immediate help from the nearest health center.

As your baby grows older, sleeping times and patterns will change. Discuss this with your doctor to know if it is of concern.

Facts About Baby Care at Home

How warm should I keep the temperature in my house?

The 23-24°C temperature is warm enough as long as the baby is dressed appropriately. One rule of thumb is to dress your baby like you are dressed for that kind of day and a similar amount of activity (usually sleeping or quiet).

How can I tell if my baby is sick?

The more you know your baby, the more you will know when you baby just doesn't seem to be acting the same. Some premature infants are more susceptible to colds or respiratory infections. A change in your baby's response or behaviour could be a sign that your baby is sick. The following signs may indicate a visit to your doctor or to the nearest Pediatric Emergency Center.

- Change in your baby's breathing pattern
- Excessive crying or irritability
- Change in eating pattern
- Difficult to wake up or not as active as usual
- Coughing, not associated with feeding
- Vomiting all or most of his/her feedings
- Frequent liquid stools within a short period of time (6-8 hours)
- Not as many wet diapers as usual and urine is a darker color
- Blue or pale colored skin
- Fever

When can I take my baby out in public?

It is best not to take your baby out in public for the first 3-6 months after bringing your baby home from the hospital. When you do take him/her out, try to avoid places which are crowded, or where they may be lots of people with colds and other illnesses, such as the mall on a weekend, or parties or nursery schools.

Should I allow visitors when my baby gets home?

When your baby gets home there will be many well meaning people who want to come and visit. Here are some tips to keep in mind:

- People with colds or the flu will have to visit at a later date.
- Your premature will be more sensitive to stimulation and may do better if not held or only held for a limited time by one person.
- The best thing to do is to limit the number of people who visit at one time and limit the amount of time they visit.
- Don't let people drink hot liquids or smoke and hold the baby at the same time

You can always say that the doctor does not permit any visitors for the time being!

My baby sounds as if he/she has a stuffy nose. Should I be worried?

It is not unusual for preterm infants to sound stuffy. You may want to add some humidity in your house to see if the stuffiness gets better (try turning on the shower, or having a humidifier). If the stuffiness continues and your baby doesn't seem to be getting any better, it is wise to call the doctor to have it checked out. It could be a cold.

Are hiccups and sneezes normal?

Yes, hiccups and sneezes are normal. When your baby has the hiccups, you can offer a little milk by bottle or allow baby to suck a bit on the breast if you are breast feeding. Hiccups may also be a sign that your baby is feeling a little stressed and needs to have some quiet time. Try to give some rest between sucking.

Sneezes are nature's way to clear the passages of your baby's nose. Sneezing also occurs when your baby has a cold.

How do I know if my baby is getting enough milk?

By the time your baby goes home, he/she may be feeding around 40 to 50 mls every 3 hours or breast feeding every 3 hours for 20 to 30 minutes. A good way to see if your baby is getting enough to eat is to observe how many wet diapers he/she has in a 24 hour period. Your baby should have 6-8 wet diapers every day. If your baby is finishing the feeding in a shorter time and still acting hungry, offer an extra 20 mls. A breast feeding baby will usually increase its feeding time by sucking longer or wanting to eat more often. This builds up your milk supply so that you can meet your baby's demand for more feeds. When you go to the follow up appointment, your doctor will check your baby's weight and let you know if the weight gain is appropriate or not.

Infant Resuscitation

Although you may never have the need to resuscitate your infant, it is nevertheless a useful skill to have especially if you a have a medically fragile infant at home. If you are interested in learning this skill, please speak to your baby's nurse so that arrangements can be made to train you.

The following action should be taken if you suspect your baby has stopped breathing:

- Check responsiveness - **DO NOT SHAKE!** Tickle a foot or shout loudly.
- If no response - stay with baby and call for help.
  Open airway - tilt head and lift chin (as if baby is sniffing the air).
- Check breathing - look, listen and feel for 10 seconds.
- If alone call **999** at this stage taking baby with you to the phone.
- Recheck your infant's breathing.
- If not breathing give 5 to 10 breaths covering the mouth and nose.
- Note if baby's chest rises. If chest does not rise alter head position and try giving breaths again. Check for signs of movement.
- If baby is still not responding, give 3 quick chest compressions.
  - Draw an imaginary line between the nipples.
  - Then press down with your index and middle fingers just below the middle of this line.
  - Give one breath and then continue giving 3 chest compressions followed by a breath.
  - Keep going until help arrives.

Glossary of Medical Terms

- Acidosis:
  An excess of acid in the body.
- Abdominal film:
  An x-ray picture of the abdomen showing the stomach and intestines.
- Anemia:
  A low concentration of red blood cells.
- Antibiotics:
  Medications that kill bacteria or slow their growth; used in treating bacterial infections.
- Apnea:
  Irregular or absent breathing.
- Bicarb (Sodium Bicarbonate):
  Medication given intravenously to treat acidosis.
- Bili-lights:
  See Phototherapy.
- Bilirubin:
  A breakdown product of the blood which can cause jaundice.
- Blood pressure:
  Measure of heart and circulatory function.
- Bradycardia:
  Heart rate less than 80.
- Calcium:
  A chemical element which is necessary for the normal function of several systems of the body such as the heart, nerves and bone.
- Central Venous Catheter (CVC):
  A catheter threaded into a major vein. The tip of this catheter usually empties directly into the heart. The catheter is used to provide fluid and nutrition when a baby cannot eat. May be referred to as a Broviac, central or PICC line.
- Chest film:
  An x-ray picture of the chest showing the heart and lungs.

- Circumcision:
  The procedure of removing the foreskin from the penis.
- Culture:
  A laboratory test used to screen for infection of various body fluids. It usually takes 2-3 days to obtain the results of these cultures.
- Cyanosis:
  A bluish discoloration of the skin and lips due to a low oxygen blood level.
- Do Not Resuscitate (DNR):
  An order written by the doctor, at the request of the family, not to revive an infant.
- Electrocardiogram (EKG):
  A record of the electrical current produced by the heart muscle used to help assess the heart's structure and function.
- Electroencephalogram (EEG):
  A record of the electrical activity of the brain which can provide information about brain function.
- Electrolytes:
  Certain body chemicals or salts (e.g., sodium, potassium and chloride) which must be present in normal concentrations for optimal function of all cells.
- Endotracheal Tube (ET Tube):
  A breathing tube inserted into the trachea (windpipe) through the mouth.
- Exchange transfusion:
  A procedure which exchanges the baby's blood with new blood.
- Extubate:
  A procedure in which a breathing tube is removed from the trachea.
- Glucose:
  A sugar which is a principal source of energy.
- Gram (gm):
  The basic unit of weight in the metric system; 30 grams equal 1 ounce.
- High Frequency Ventilator (HFV):
  A high-frequency breathing machine that provides rapid breaths to certain critically ill babies.

- Hyper alimentation:
  An intravenous nutritional fluid given to infants to help them grow; also called **Total Parenteral Nutrition**, or **TPN**.
- Hypercalcemia:
  A blood calcium level above normal.
- Hyperglycemia:
  A blood sugar level above normal.
- Hypertension:
  High blood pressure.
- Hypocalcemia:
  A blood calcium level below normal.
- Hypoglycemia:
  A blood sugar level below normal.
- Hypotension:
  Low blood pressure (see Blood Pressure).
- Incubator:
  A special type of enclosed bed that regulates the baby's temperature and provides noise reduction.
- Informed Consent Form:
  a form that assures your NICU team that you understand the required procedure for your baby.
- Intramuscular (IM):
  A method for giving medication into the muscle.
- Intravenous (IV):
  A method for giving medication and/or fluids into a vein.
- Intubate:
  A procedure in which a breathing tube is placed into the trachea. The patient is then placed on mechanical ventilation.
- Jaundice:
  The yellow color of the skin caused by too much bilirubin in the blood.
- Kilogram (kg):
  A unit of weight in the metric system; One kilogram equals to 2.2 pounds.

- Leads:
  A set of wires placed on a baby's skin that connect to a monitor which records heart rates and respirations.
- Multidisciplinary rounds:
  The daily meeting of doctors, nurses, you and other hospital personnel to discuss your baby's condition and treatment.
- Monitoring equipment:
  Used to continuously measure the baby's heart and breathing rate.
- Murmur:
  An abnormal heart sound that can be heard with a stethoscope.
- Nasogastric Tube (NG Tube):
  A plastic tube which is passed through the nose into the stomach and is used for giving feedings and medicines, or for removing stomach fluids.
- Neonatology:
  The pediatric sub-specialty concerned with medical issues of the newborn baby.
- Nitric Oxide (iNO):
  An inhaled gas therapy which increases blood flow to the lungs and improves blood oxygen levels.
- NPO:
  An abbreviation meaning the baby cannot be fed by mouth.
- Patent Ductus Arteriosus (PDA):
  Failure of a heart blood vessel to close after birth. This may require medical or surgical closure.
- PCO2:
  A measure of the carbon dioxide in the blood.
- Phototherapy:
  Fluorescent light therapy which is used to treat jaundice.
- Pneumonia:
  Inflammation of the lungs which may be caused by infection.
- PO:
  An abbreviation meaning to deliver by mouth or with feeding.
- PO2:
  A measure of the oxygen in the blood.
- Polycythemia:
  Too many red blood cells in the blood.

- Potassium:
  One of the body's electrolytes (see Electrolytes).
- Pulse Oximetry:
  Measures blood oxygen content through the skin.
- Red blood cells:
  The cells in the blood which contain hemoglobin and carry oxygen.
- Residual:
  The amount of formula remaining in a baby's stomach after a feeding. Also called an aspirate.
- Respiratory Distress Syndrome (RDS):
  Respiratory failure due to lung immaturity or infection.
- Retracting:
  The "pulling in" of a baby's chest during breathing.
- Room Air:
  The air we all breathe which has an oxygen concentration of 21%.
- Sodium:
  One of the body's electrolytes (see Electrolytes).
- Saturation:
  Oxygen levels in the blood stream.
- Lumbar Puncture (LP):
  Insertion of a small needle through the back into the spinal canal to obtain a sample of spinal fluid. Also called a spinal tap.
- Suction:
  Removing mucus from the nose and throat or from an endotracheal tube.
- Surfactant:
  A substance lining the lungs, which is often absent or decreased with infants in respiratory distress. Surfactant is also a medication which is instilled in the lungs as part of treatment.
- Transcutaneous Monitor (TCM):
  A monitor with a special sensor that is placed on the skin to provide a continuous reading of oxygen or carbon dioxide in the blood.
- Warmer:
  A special bed with an overhead heater, which keeps the baby's temperature controlled.

Telephone Numbers

• Baby Clinic	: 4439 3039
• BIRTH REGISTRATION	: 4439 3062/4439 3229
• CASE MANAGER	: 5010 1764
• NICU – UNIT 1- TBU	: 4025 3437/4025 3438
• NCCU	: 4025 3435/4025 3436
• NICU-UNIT 2	
• ICU A	: 4439 3158/4439 3245
• ICU B	: 4439 3257/4439 3095
• NICU-UNIT 3	: 4439 3328/4439 6135
• NICU-UNIT 4	: 44439 3594/4439 3595
• NICU-RECEPTION	: 4439 3621
• SOCIAL WORKER	: 4439 6977/ 4449 6849
• EMERGENCY AMBULACE SERVICE	: **999**

Notes

Notes

Neonatal Intensive Care Unit (NICU)

4439 3621 / 4439 3249

patienteducation@hmc.org.qa

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