UNDERSTANDING THE NICU:
from crossroads to milestones of *Premature babies*

Information for Parents/Guardians
Introduction to the NICU

Congratulations on the birth of your baby or babies. Your children are beautiful and resilient.

We understand that your birth experience has taken an unexpected turn and you may be overwhelmed about finding yourself and your newborn(s) in the NICU.

We have put together this booklet to answer some of your questions and help ease your fears. Our goal is to offer guidance and information for the days ahead.

What is the NICU?

NICU stands for neonatal intensive care unit. It is a specialised unit in the hospital that treats ill and premature newborns.

Who we are?

We are a group of individuals with specialised skills and expertise to take care of your newborn. Our NICU has state-of-the-art equipment, efficient monitoring, highly skilled clinicians and nurses.

The Aga Khan University Hospital's NICU offers the highest quality of inpatient and intensive care.

Who will care for your newborn in the NICU?

NICU Team

Your newborn will have a primary team. This comprises of attending neonatologists, subspecialists, neonatal fellow trainees, postgraduate resident trainees, nurses and a dedicated NICU unit clerk.

Also included is an ancillary team of pharmacists, physical therapists and sonographers.

What to anticipate when you come to the NICU?

When you first visit your newborn, you will likely see multiple tubes and machines attached. These provide medications, nutrition and support to your baby and allow us to closely monitor your newborn closely.

NICU survival data for Preterm:

Below is the 4 years survival data for preterm babies at our center. While the chances of survival at 24 weeks are low, after 27 weeks they increase substantially.

The outcome for premature births are generally good, however there are risks to being born early. Below are details of some common complications seen in preterm babies.

Common problems in the NICU

Temperature Instability

Premature babies are unable to maintain their temperature adequately. Therefore they are placed in incubators till they are able to regulate their body temperature on their own.

Kangaroo mother care (KMC) is particularly encouraged in our NICU. There is
evidence that skin to skin contact with mothers reduces the morbidity and mortality in premature babies and promotes breast feeding.

**Breathing problems**
Respiratory Distress Syndrome is a common problem in premature babies. This occurs because the newborn’s lungs have not matured and do not produce a substance called surfactant. Surfactant enables lungs to expand easily. Such infants will need support to breathe, this may include ventilators, CPAP machine or nasal cannulas.

Premature babies also experience apnea of prematurity (meaning cessation of breathing). This happens as the breathing centers in the brain are immature, premature babies sometimes forget to breathe. This is usually treated with caffeine and respiratory support.

**Feeding Problems**
Premature babies are not able to simultaneously coordinate breathing, sucking and swallowing; hence most of them are initially fed through a feeding tube.

They also get nutrition through IV fluids called Total Parenteral Nutrition (TPN). This provides the necessary energy and calories, protein, fats, carbohydrates, calcium and micronutrients for their growth.

It is extremely important for mothers to start pumping breast milk soon after delivery. Our nursing staff is trained to assist and support mothers in breast feeding and pumping. Breast milk has tremendous health benefits for babies, especially those that are preterm.

In preterm infants, breast milk is associated with
- Reduced infection and inflammatory disease
- Enhanced neurodevelopmental outcomes
- Healthy early postnatal growth patterns
- Reduced incidence of Necrotizing Enterocolitis (NEC)

**Infection**
Infection is a common occurrence in NICUs globally. The immune system of the premature baby is immature, making them vulnerable to infections. Most infections respond to treatment with antibiotics and supportive care, however sometimes it may be quite serious. We ensure our babies remain safe by following strict hand washing practices, basic hygiene and traffic control in the NICU. Our unit clerk will orient you to the visiting guidelines, so that you can also help us in keeping our NICU infection free.

**Necrotizing Enterocolitis (NEC)**
This is a serious complication of prematurity that is caused due to inflammation of the gut wall. It can vary in severity. We sometimes have to stop feeds, give antibiotics and observe the baby. In some cases surgical management is needed. Research has proven that breast milk is protective against NEC.

**Intraventricular Hemorrhage (IVH)**
This is bleeding inside the head; due to fragile blood vessels in a particular area of the brain. The chances of bleeding are higher with lower gestational age. For this purpose we screen babies born before 32 weeks and weighing less than 1,800 grams with bedside head ultrasound on days 3, 7 and 21.

IVH varies in severity from Grade I to Grade IV. Depending on the grade, the ultrasounds will be repeated periodically to follow the progression of IVH. Grade III and IV are associated with a higher risk of neurodevelopmental sequelae.

**Patent Ductus Arteriosus (PDA)**
Ductus Arteriosus is a blood vessel, which is vital for appropriate blood
circulation while the babies are in the womb. In healthy term infants this vessel naturally closes after birth, however in premature infants the closure is delayed or does not occur which results in a condition called PDA. This can cause some respiratory and feeding problems for the baby. If the problems are significant, we may administer medication or suggest surgery to facilitate its closure.

Retinopathy of Prematurity (ROP)

Retinopathy of prematurity (RoP) is an eye disease that can happen in premature babies. It causes abnormal blood vessels to grow in the retina, and can lead to blindness. Premature babies and or those exposed to high concentration of oxygen are at an increased risk for developing this condition. Hence, babies that are less than 32 weeks gestation and less than 1,500 grams are screened at 4-6 weeks after birth for RoP. This examination is done at the bedside, if your baby is admitted in the NICU or in the Ophthalmology Clinic following discharge from the hospital. It is extremely important to follow up with your ophthalmologist in case treatment such as intraocular injections or laser surgery is required to save vision.

Jaundice

Jaundice is common condition that causes the skin and eyes to become yellow. It happens when a baby's liver is not mature enough to break down bilirubin. Jaundice is treated with phototherapy lights which break down the bilirubin.

Sometimes when the bilirubin level is very high, babies may require treatment with intravenous immunoglobulin (IVIG) or even exchange transfusion.

The parents’ role in the NICU

Don't be discouraged, you can bond with your baby. Don't let the equipment and activity in the NICU keep you away from interacting with your little one.

Bonding with parents is important for all newborns, and even more so for premature babies. Check with your baby's caregivers to decide how best to spend the time.

STEP-DOWN UNIT

Most NICU babies are transferred to a step down NICU unit before discharge. This means the babies are stable enough and no longer need one on one nursing care. You are one step closer to going home.

Here the parents are trained on how to care for and feed the newborn, breast feeding and KMC is particularly encouraged.

Some babies are discharged on orogastric tube feeds; hence mothers are trained on the feeding regimen and care.

Mothers also undergo neonatal resuscitation training in the step down unit and are trained to recognise apnea and danger signs in the infants.

Our nurses will provide you with discharge instructions including take home medications and a list of follow up appointments.

Your baby will be ready for discharge when the baby:
• continues to gain weight adequately
• tolerates feeds by gavage feeding or cup and spoon
• maintains body temperature in an open crib
• breathes well and is pink and active

A SAFE PASSAGE HOME