

Your baby in neonatal care (English version)



Your child has been born and admitted to the neonatal intensive care unit (NICU). Maybe your baby was born too early or born too small, for instance due to an illness. You have stepped into a strange new world where doctors and nursing staff seem to play the leading role. While both you as parents and your child were unprepared for this situation, it has happened to you anyway.

Many parents will feel confused, worried and scared, and have many questions. Everyone deals with this differently. Some people switch to autopilot and feel like everything is passing them by, others are overcome with fear, sadness, anger, disappointment, guilt and sometimes, despite everything that has happened, joy and pride for their child. These are all perfectly normal reactions.

Allow yourself the time and space to put this overwhelming event into the right perspective. And, amidst all confusion, take on the task of being a parent to your child. After all, it is *your* child.

While nurses and doctors are there to take care of medical and health care issues, the child's parents are the most important link in this chain for your newborn. Nurses will never be able to take over your job as a parent.



Even the tiniest babies feel and hear when their parents are with them. It soothes them. Together with the neonatology team you can take care of your baby.

One of your responsibilities as a parent is to ask questions: Ask what is happening and why, and if you forget what the answer or find it hard to understand what you have been told, ask again; the next day, if necessary. There may be issues that are important to the medical staff because such issues may be handled differently in your country, or according to your religion or culture. For instance, in some cultures, the father isn't allowed to touch the baby in the first few days after birth, the child isn't named immediately or the head of the child is

shaven bald. This is not something western cultures are familiar with, but it is usually open to discussion.



No matter how much you would like to present your baby to the world, this is not the procedure on most NICU's. Many children are very ill and what they require most is peace and tranquillity. Ask the nursing staff for visitor regulations if you want to bring in a family member.

Children in a NICU

The neonatal intensive care unit admits children who need extra medical attention after birth. These include prematurely born children, but also children who experience medical problems after birth (infections, oxygen deficiency, etc.) or children whom the doctors suspect may have a congenital defect.

Sick children

Sick children are also admitted to the NICU and in these cases the treatment focuses on the illness. Depending on the situation, a child is admitted either to intensive care or to a 'regular' neonatal ward.



Premature children

A child is premature if they are born before the 37th week of a pregnancy. In general, the shorter the pregnancy, the more problems a child will face.



In Holland it is customary to treat children if they are born after at least 24 to 25 weeks of pregnancy. A child that is born so prematurely is admitted to a special intensive care ward for babies (NICU), where there is specialised equipment such as respirators and expert medical care. A child born after a pregnancy of (approximately) 32 to 36 weeks who is not expected to have any major complications is placed in the neonatal ward of a regular hospital (medium care).

An imminent premature birth

Although there are many possible reasons for a premature birth, in most cases the case is unclear. Possible causes include:

- Premature labour
- The waters break prematurely
- The umbilical cord is insufficiently saturated
- The placenta is not working as it should or is detaching
- The mother has a dangerously high blood pressure

The cause can lie with the child. Sometimes when a child is unwell, they need to be born prematurely.

If possible, a premature birth is slowed down with medication that should stop the contractions, and the mother will be given injections with hormone preparations (corticosteroids) to speed up the development of the child's lungs.

Underdevelopment is the main problem after a premature birth. Of course a child of 35 or 36 weeks is much more developed than a child of, say 26 weeks, and every day that a delivery is delayed benefits the child.

What happens at the NICU?

Not everything listed below will apply to your child. We are merely trying to explain a number of common challenges facing prematurely born babies.



- Nutrition

Very premature babies are not able to drink as stomachs are not working sufficiently. As a result feeding starts with tiny amounts of food that are directly transported to the stomach via a tube. It is recommended that mothers start using a breast pump as breast milk is the best possible nutrition even for premature babies. If this proves impossible, the baby will be fed with specially adapted formula.



In some cases the baby is fed via an intravenous (IV) drip in a vein in the baby's arm, leg or head, and sometimes via the umbilical cord. When the baby is 33 or 34 weeks old (measured in weeks of pregnancy) an attempt is made to have the baby drink either straight from the mother's breast or from a bottle.

- Lungs

A major problem among premature babies is underdeveloped lungs. Very young babies have underdeveloped alveoli that tend to open insufficiently. In such cases the baby will receive medication. Another problem may be that a baby 'forgets' to breathe: This is called 'apnoea'. Because they are connected to a monitor, however, measures are taken as soon as they



stop breathing. If necessary they are connected to a respirator, or receive breathing support by means of tubes in the nose (CPAP or NPAP). A heart rate slowing down due to respiration problems is called bradycardia (usually shortened as 'brady').

(respirator)

- Arteries/brains

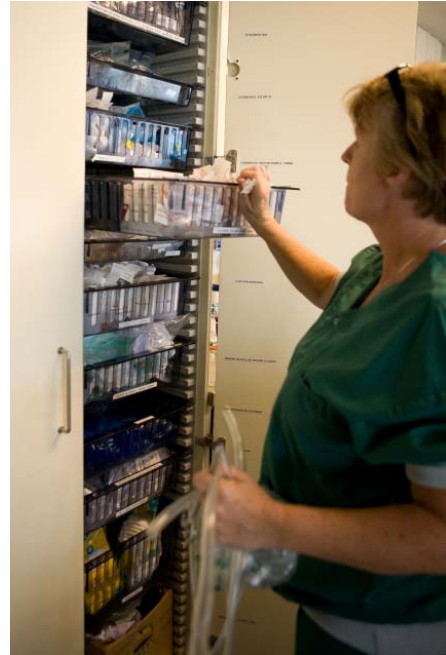
The brains and arteries of very premature babies are underdeveloped, which can easily result in brain haemorrhages. Small bleeds do not necessarily have an impact on a child's development. A cerebral haemorrhage can be detected via ultrasound measurements, which will be regularly taken. The doctor will share the results and his expectations with the parents.



(Ultrasound)

- Heart

Premature babies may also suffer from heart problems. Sometimes an artery near the heart, the so-called 'Ductus Botalli', does not close: This is called an 'open Ductus'. Before birth, this artery serves as the connection between the pulmonary artery and the aorta, bypassing the fetus' fluid-filled lungs. After birth the blood should absorb oxygen from the lungs whilst passing through the lungs instead of the Ductus. This is only possible if the Ductus has properly closed itself, a process that happens automatically once a baby begins breathing by itself. Should the Ductus fail to close automatically, the baby will receive medication in order to help this. Another option is to temporarily provide the baby with fewer fluids. If this does not work the only remaining option is to close the Ductus surgically.



- Infections

Due to their premature birth and while staying at a NICU, premature babies may be at risk of infections. They are more susceptible because of their reduced



defence as a result of a shorter pregnancy. Furthermore, infection quickly affects the entire body of a premature baby. As a preventive measure, they are given antibiotics as soon as an infection is suspected. So long as you follow normal hygiene practices you should be able to handle your child normally. Kangarooing and other physical contact do not result in extra risks and it is essential to the bonding process between parents and child.

- Muscles

After birth a child is no longer curled up in the amniotic fluid in the womb. Because this pose is important for the development of muscle strength, babies in incubators are often placed in a 'nest'. Sometimes a physical therapist is consulted as well.

- Eyes and ears

Premature babies are extremely sensitive to light and noise, which is why the incubator is covered to protect them from too much light and noise levels are kept to a limit. In addition, the arteries in the retina of premature babies are not yet fully developed so an ophthalmologist will check the development of these arteries regularly. Hearing is also tested before discharge.

Premature birth can also cause other medical issues as not all organs are fully developed at the time of birth. This is why the intestines, kidneys and liver of a premature baby are monitored.



What can you do?

Your role as a parent

Many parents find it difficult to make contact with their child. They are afraid to love their baby because they still fear they may lose them. Premature babies look tiny and fragile and physical contact with them is often limited.

Parents are also intimidated by the equipment and busyness on the ward. They sometimes feel as if their baby isn't theirs and that they are merely visitors.



Do not underestimate how important

you are as a parent. Even the smallest children can feel, smell and hear their parents, and this is often visible in their medical charts.

When you are present they are calmer, breathe more regularly, sleep better and are more tolerant to nutrition. Try to be with your child as often as possible. Remember you are not just a visitor - you are a mum or dad!

The nurses can give you tips on how you can best make contact with your child. They will also teach you one step at a time how to care for your child independently, including how to change their nappies, take their temperature, bathe them and feed them. The nurses are there to help children and parents alike.



Breast feeding

Breast feeding is very important to babies in incubators: Only breast milk contains certain ingredients that can protect them from specific infections. Mothers therefore have to express milk very often, which is not easy for them. Sometimes a baby may need more than just breast milk, and vitamins and minerals are added. The basis, however, remains breast milk (of course there is formula available if a mother has problems expressing milk).

Contact

Kangarooing is very important. It involves a child lying against the bare chest of their mother or father, allowing them to feel their breath, hear their heartbeat and smell them. It is a good way to calm your baby. Like with other forms of physical contact, kangarooing does not result in additional hygiene risks and is vital in the bonding process between parents and child.

You can also talk to your baby, read them a story or sing to them. Although they won't understand you, they can sense your presence and support. The voice and heartbeat of the mother are especially comforting to a child. Every form of contact with your child will allow you to get to know them better.



Hygiene

Good hygiene is crucial if very young babies are to avoid infection. Jewellery (rings, bracelets, watches) in particular contains a large amount of bacteria as they are difficult to keep clean. This is why jewellery cannot be worn in the NICU. Nail polish is 'prohibited' on many wards because there are many bacteria beneath it. Follow the guidelines of the ward closely, including washing your hands, wearing protective clothing, etc.



Clothes? Toys?



Is your baby allowed to wear clothes? Can you make something yourself? Some wards provide patterns. An increasing number of specialised baby shops also sell very small sizes as do many normal baby shops. There are also certain dedicated sites on the internet, such as www.pre-be-exclusief.nl or www.pre-kids.nl. They are specialised in the supply of very small sizes, even for the smallest babies of, for instance, 28 centimetres. They can deliver within two days.

It is nice to put something personal in the incubator, such as a cuddly toy (some hospitals only allow toys that can be cleaned or washed).

Transfer to another hospital

If your child was admitted to an intensive care unit (NICU) and it is doing well, the highest level of care will no longer be needed. The doctor will tell you that your child will be transferred to another hospital where they will be cared for further until their health is sufficient for them to go home. Initially this may frighten many parents: they have become accustomed to the current situation and when their child is finally getting better, they have to leave. You should consider that it is a good thing that your child can suffice with 'normal' care at another hospital. The incubation unit where they were staying can now be used for another child.



Moreover, the new hospital will be closer to your own home, making it easier for you to be there for your child.

If possible, consider visiting the new hospital before your child is transferred. Hospitals often have different rules regarding hygiene and visiting, and there are usually less medical personnel per child. There may not be constant medical staff on the neonatal ward, but staff will have pagers that warn them if anything happens.



When your child is ready he or she will be taken off the monitoring equipment and placed in a crib. If this goes well and the baby drinks enough independently, you can usually take him or her home.

Tips for home

- Nursery and crib: Make sure your child is not too warm; a temperature of between 20- 22° C is ample. Not too many blankets, no duvet or pillow. Make sure there is enough fresh air.
- Children should sleep on their back, not stomach or side (as they might roll over and land on their stomach). A child should not sleep in the same bed as their parents: it is usually too warm, there are pillows and duvets that could cover them and they will not be able to regulate their own temperature.
- Bathroom (or where you bathe your child): Make sure it is nice and warm.
- Do not dress your child too warm (nor overly cold)
- Rest, cleanliness, routine.... Do not over-stimulate your child. Be aware of the signals: If children are not interested in your actions then they are tired. Tired children often turn slightly paler and they may look away. If this happens let them rest.
- Don't feed and then play with your child, no matter how much you may want to. Don't rock them, walk around and talk to them at the same time. It is often sufficient if the child can see you.
- Do not pass your child from one person to the next when you have visitors. This is too exhausting and will make them cry.

- So long as your child is fragile, do not have any sick people or people with a cold as visitors. Do not feel like you are being overprotective and do not hesitate to be strict!
- Do not allow smoking in the same room as the baby (not even when the child is in another room). Do not take your baby anywhere where there will be people smoking.
- The paediatrician or neonatologist is the first responsible doctor. Have the personnel of the (baby) health centre or your family doctor contact them if there is any uncertainty.
- There is no such thing as a stupid question. As a parent you know your own child best and it is better to ask unnecessary questions that wish you had asked them later.
- Vaccinations will be performed at calendar age.
- In their first two years, it is best to correct your child's age; this means that you deduct the number of weeks your child was born prematurely from the calendar age (or calculate from the expected birth date). This applies to nutrition guidelines and the child's development. If all goes well, the development will quickly be up to speed.
- Sometimes the growth development may be a bit slow. This is fine. Giving children sweets or fatty foods (butter, cream) is not a good way to make them grow. Healthy and varied meals and as much fresh air as possible will make your child strong. Make sure he or she does not become overweight.
- Due to the risks of bacteria never give children jewellery in their first year or have their ears pierced.
- A physical therapist can give advice if your child isn't moving flexibly or if their motor skills are not fully developed.



(Private photo)

And most importantly of all, remember to enjoy your child! Their struggle for life deserves your respect. Your child is a fighter. And you too deserve respect for everything you have been through with your child!

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