Diary for Families with Preemies

A Dräger Review Edition
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So normal. Your heart beats.
You draw breath.
So normal, you hardly think about them.
Life.
So wonderful. And so fragile.
So fragile, it’s all we think about.
Welcome to the world

Age of the embryo in weeks

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Developmental stages

The gestational age is the term used to describe the age of the developing child: The counting begins when the egg is fertilized. From that point onwards, a distinction is made between three phases.
Dear Family,

Congratulations on the birth of your baby! Both mom and baby went through a lot of physical effort, during the pregnancy and birth. You can be proud of yourselves. Of course, what you want to do more than anything at this point is take your baby home as quickly as possible. After all, you’ve been looking forward to this moment for months, enthusiastically counted down the days until the birth and have already prepared nearly everything for your baby’s arrival.

But your baby came too early. Your baby still needs time to fully develop outside of mom’s womb. Naturally, this affects your joy and happiness.

Several doctors and nurses care for your baby in the premature infant ward. They are doing all they can to help him or her develop well. You, the parents, are an irreplaceable part of this care.

Use this diary to keep track of what’s happening during your time in the hospital. In some situations, it will provide you with tips, in others, it will help calm your anxiety and fears.

Enjoy reading and filling out this diary!
There are especially strict hygiene and cleanliness rules in the premature infant ward. Premature infants' immune systems are not yet fully developed, meaning that they need this extra protection. It is important to thoroughly wash your hands and then disinfect them to remove all bacteria and germs so as to protect your baby from infection. Wearing rings and jewelry on your hands makes it more difficult to kill all germs and bacteria, so it is a good idea to take them off for the time being.
INCUBATOR

Warmth is especially important for premature infants. When your baby is in your womb, he or she adapts to your body temperature, which keeps him or her warm. If your baby is born early, it is important to keep his or her body temperature consistent. Cold causes stress in premature infants. This is why babies are often placed in incubators. The distance the incubator places between you and your baby is only temporary until he or she is able to regulate his or her own body core temperature.

The purpose of the incubator is to imitate the ambient conditions your baby experienced in your womb as closely as possible. The incubator is a perfectly temperature-controlled protective space where your baby receives the correct amount of heat and humidity and sometimes even oxygen. A large part of medical care of premature infants happens directly in the incubator to protect him or her from risks, such as changing room temperatures or a bacterial or viral infection. Some incubators even generate a so-called “warm air curtain” which reduces heat and humidity loss when the lid or access holes are opened.

The climate in the incubator is continuously monitored so that your baby can develop in the optimal conditions. This monitoring also includes temperature measurements. It is important to measure the temperature in more than one place on the body, as it varies from organ to organ. If a change in body temperature is detected, the climate in the incubator can be adjusted. This is done using various methods which regulate air supply to a specific level and can reduce or increase the heat.
DIARY FOR FAMILIES WITH PREEMIES

TEMPERATURE
Amniotic fluid has a temperature of 37.5 degrees Celsius*. A premature infant is only familiar with this comfortable temperature. Your baby is not yet able to regulate his or her body core temperature – he or she can’t even shiver or sweat. This is why the incubator has similar temperatures to those in the womb. Premature infants demonstrate cold stress by shaking or through increased muscle tension, for example. When they do this, babies expend calories which are intended to help them grow. This is why time outside of the incubator must be limited to protect the baby from the cold. During so-called “kangarooing”, the baby feels the warmth of mom or dad.

NOISE
Sounds help premature infants to develop their sense of hearing. Babies are especially comfortable when they hear their parents’ voices or quiet melodies. However, they become stressed if the ambient sounds are too loud. Even the volume of a normal conversation is loud noise to a baby. If someone places something on the incubator or knocks it, this is extremely uncomfortable and painful for the premature baby.

LIGHT
It is almost completely dark inside the womb. This is why babies who are born early are still very sensitive to brightness. Bright light causes them stress. They make this noticeable by moving their heads or eye lids, for example. That is why premature infants are protected from abrupt light exposure. However, daylight is generally a positive factor for their development. It is good for the skin and lets the baby know when it is day and when it is night.

HUMIDITY
Increased humidity is important for premature infants, since their skin is not yet fully developed. Too little humidity can damage skin, cause infections or lead to dehydration. Dehydration causes the baby to cool down because of humidity evaporation, thus lowering his or her body temperature. This is why incubators have very high humidity – even up to 100 percent for some preemies.

Stress and comfort factors

*temperature corresponds to 99.5 degrees Fahrenheit
MONITORING

Various vital functions of your baby are constantly monitored. The monitors in the premature infant ward show your baby’s heart rate and respiratory rate, blood pressure, and the oxygen levels in his or her blood. Depending on his or her health condition, other parameters which the doctor considers necessary may also be monitored. That is why your baby has sensors on his or her body or is wearing a cuff on his or her arm which measure these values. Cables connect them to the monitor.

Several monitor functions in the premature infants’ ward occasionally trigger alarms which are set individually for each value. These alarms are intended to give parents and the nursing staff as good of an idea as possible of the conditions inside the incubator or the baby’s thermal bed. Several of these alarms are sounded in the central wards, e.g. in the nurses’ room, and not directly on the monitor.
MY SENSES

A lot of impressions rain down on me in the premature infant ward: The alarms from devices, the voices of strangers, the light and the continuous examinations and even interventions. Even though I was born early, I absorb everything and need your love and care to process these impressions.

Even in my mom’s womb, I could touch, hear, see, taste and smell. In my mom’s womb, I practiced moving and training my senses. With my skin I felt touch, warmth and cold from early on. I could even hear voices and sounds and became aware of the differences between light and dark. I only perceived a lot of these impressions through the buffer of my mom’s womb. I reacted when you placed your hands on my mom’s belly. So I pressed back and kicked with my legs.

Because I was born early, I only experienced part of some of the impressions other babies have while in their mothers’ wombs. So I have a lot of catching up to do. I need time and rest to grow and gain weight. And I need the stimulation of your voices, the touch of your hands, and a lot of cuddling to fully develop my senses.
I HEAR

In my mom’s womb, I was already exposed to a lot of sounds: Her heartbeat and the sounds her stomach and other internal organs made. Between the 20th and 24th weeks my ears are fully developed and respond to noises. I need your support to develop my sense of hearing. It is especially your voices which help me. Starting in the 26th week, I react to you visually. I didn’t only hear my mom’s voice in her womb, but I could also feel its vibrations through her spinal column and pelvis. She was with me the entire time that I spent in her womb and is a very familiar person to me. I can immediately tell her voice apart from other women’s voices. I have also heard dad’s voice a lot and can easily recognize it.

Starting in the 5th month, I react to music. If my mom played or sang certain songs often during her pregnancy, I remember them. These songs calm me down when I’m restless. I am especially fond of quiet, harmonic sounds. But what I like most is when you sing or read something yourself. This makes my heartbeat more regular and my movements more relaxed. I left my mom’s protective womb too early. It was dark and quiet in there. That is a comforting environment for me because my hearing is still very sensitive. I get restless when the environment surrounding me is loud. That is why incubators often have a noise indicator which monitors the volume in the room and in the incubator. A yellow and red light indicate that it is too loud for me. Green means that everything is OK and I can sleep peacefully.
VENTILATOR

When a baby is born too early, his or her lungs are not yet fully developed. He or she needs help breathing. A ventilator ensures that your baby receives the correct amount of oxygen for his or her development.

With invasive breathing support, a cannula creates access for the baby to receive oxygen through a tube which is fed through his or her mouth or nose and into the windpipe.

Non-invasive breathing support works with a breathing mask which ventilates the premature infant with sufficient oxygen and ventilation pressure.

Both methods make the baby’s chest rise and fall. It is often difficult for you as parents to watch as your baby wears a breathing mask or is ventilated through a tube. This is understandable. But this is the only way to provide your baby with the amount of oxygen he or she needs. When your baby’s lungs are fully developed, the doctors and nurses will begin to wean him or her. This is the phase in which the baby will slowly get acquainted with breathing independently without the ventilator.
PHOTOTHERAPY

Many premature babies have jaundice just after birth. This means that their skin is tinged yellow. But where does this color come from?

Newborns continuously produce new red blood cells, and the old ones die off. One of the waste products from old blood cells is a yellow substance called bilirubin. The liver transforms bilirubin into a form which is easy to discharge. It then leaves the body with the stool. Some newborns generate bilirubin faster than they can discharge it. When this happens, the bilirubin builds up in the body and gives the skin a yellow color. The yellow color can be seen best in daylight (close to a window) or under the fluorescent lamps in the premature infant ward. Normally, the excess bilirubin can be broken down by sunlight.

Because premature infants are very sensitive, they are given phototherapy. Phototherapy systems radiate a warm blue light over your baby. This supports the breakdown of the excess bilirubin, which is then discharged through the intestine. The phototherapy light has proven to be a very good method for supporting premature infants’ processing of excess bilirubin. Jaundice in newborns is not usually a cause for concern.
INFANT WARMER

A perfect ambient temperature for your baby is the most important factor during his or her time in the premature infant ward. Newborns, and especially premature infants, need stable ambient conditions. The most sensitive premature infants spend a lot of time in incubators for closed care. Once your baby is strong enough, many doctors choose open care. This is where thermal beds come in. Once your baby’s condition has stabilized, his or her organs have developed further, and he or she is less susceptible to external influences, this means they can spend some time in open care. This makes it much easier for parents to care for their baby while he or she continues to receive the heat they need to continue developing.

The temperature of the thermal bed can be set to a value which, as opposed to the room temperature, is perfect for newborns. By now, several thermal beds have been calibrated so that this value is set automatically, even when your baby is already inside.
Dear Family!

Finally you get to say goodbye to the premature infant ward and head home! Time spent in the clinic is an enormous physical and emotional strain for every family. But you’ve made it. Despite the huge relief to be going home and no longer having to stick to the clinic’s routine schedule, you may be feeling a slight sense of uncertainty. After all, others have taken over a large part of the responsibility and care for your newborn up until now. You first need to develop a sense of calmness and trust in your own instincts. This will take some time. And your baby will of course also need some time to get used to his or her new environment at home. All you can do is be patient now.

Your baby doesn’t care if you couldn’t find time while you were in the hospital to buy baby clothes or finish setting up his or her room. What he or she needs most is lots of love and affection in his or her new environment at home. And you also need time now to rest and process everything you’ve experienced.

This diary is intended to be a memory of the first days spent with your baby. Good luck and have fun settling in at home!
What does that mean?
Glossary of NICU Terms

APGAR score: A numerical overview of a newborn’s condition at birth. This score is based on various values measured after 1 minute and after 5 minutes. (Other measurements are then taken every 5 minutes if the score after the first 5 minutes is lower than 7. These measurements are taken until the score is above 7.) Premature newborns usually have a lower score than babies who are born at full term, but the APGAR score is not an exact indicator of a baby’s further development.

Bilirubin: A yellow, chemical substance which is a normal waste product when hemoglobin and other similar materials are broken down in the body. The placenta removes the bilirubin from the blood of the fetus, but, after birth, the baby needs to do this on his or her own. The newborn’s liver usually needs one week or longer to adjust to this new task. If the bilirubin builds up, the baby’s skin and eyes are tinged yellow. This is called jaundice.

Blood gas: A blood test which ascertains the oxygen, carbon dioxide and acid values of the newborn. This test is very important, because it evaluates the newborn’s ventilation status.

Continuous Positive Airway Pressure (CPAP): Oxygen supply or ambient air supplied by pressure. The air or oxygen is supplied with an endotracheal tube (a tube which is inserted directly into the newborn’s lungs) or small tubes or prongs which rest in the newborn’s nose. The pressurized oxygen supply holds the pulmonary alveoli open and keeps the airway to the lungs clear. The nasal CPAP (NCPAP) treatment is usually started immediately after the endotracheal tube is removed to treat apnea (breathing arrest) and/or prevent the need for an endotracheal tube and a ventilator.

Electrocardiogram (ECG): A test which records the electrical heart activity. This test can indicate irregular rhythms (arrhythmias or dysrhythmias) or detect heart muscle damage.

Endotracheal tube (ETT or ET tube): A tube which is inserted through the mouth or nose of a newborn and into his or her throat and trachea (windpipe). This tube creates a safe passage for the air to get into the lungs.

Expiration: exhalation.

Inspiration: inhalation.

IPPV (Intermittent Positive Pressure Ventilation): A type of controlled ventilation using a ventilator or bag-valve mask.

Jaundice: Also known as hyperbilirubinemia. Jaundice results from the buildup of the natural waste product bilirubin. When red blood cells and other tissue are replaced, the waste products of this breakdown are usually discharged through the liver. Bilirubin has a yellow color. If the values are elevated, the skin and other tissue turn yellow in color. Light jaundice can be expected in all newborns. But if the jaundice is more severe than normal, it can be treated using phototherapy (special lamps). Phototherapy supports the liver in discharging bilirubin so well that elevated values are only seldom problematic. In premature infants, the bilirubin value may stay elevated for several weeks.
**Kangarooing:** When “kangarooing” premature infants lie on a parent’s chest or belly. This way they feel the warmth of their mother or father.

**Nasal cannula:** A tube for both nostrils which is placed around the baby’s head and fastened behind the ears, to nose and neck to supply him or her with oxygen. It is used with babies who can breathe on their own but still need a bit of extra oxygen.

**Oximeter (pulse oximetry):** A device that monitors the amount of oxygen in the blood. A tape-like cuff is wrapped around the baby’s toe, hand or finger. With this device, staff in the premature infant ward can monitor the oxygen levels in the baby’s blood without having to draw blood for lab testing.

**Parenteral Nutrition (hyperalimentation):** A solution which is injected directly into the bloodstream and contains the necessary nutrients such as protein, carbohydrates, vitamins, minerals, salts and fat. This is also called hyperalimentation, parenteral nutrition and intravenous nutrition.

**PEEP (Positive End Expiratory Pressure):** A type of ventilation which maintains a slight overpressure in the lungs even during exhalation.

**Periodic breathing:** An irregular breathing pattern that is characterized by pauses of 10 to 20 seconds. This is common in premature infants and babies born at full term and does not necessarily indicate a problem.

**Persistent Pulmonary Hypertension in Newborns (PPHN):** High blood pressure in the lungs which narrows the small blood vessels in the lungs. This can cause breathing problems and reduced blood oxygen levels. Is sometimes treated with nitrogen oxide, an endogenous gas, which can support the dilation of blood vessels.

**Prong:** When a baby is ventilated through the nose, air is delivered to the baby’s lungs through a so-called prong which is placed in the nostrils.