Born too early

Information for preemie parents

Bundesverband “Das frühgeborene Kind” e.V.
Imprint

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Greeting
by the Federal Health Minister Ulla Schmidt

Dear parents,

There are few moments in life where happiness and anxiety are so close together like in a preterm birth. For many weeks not only the belly was growing, but also the anticipation of the baby’s arrival. You have been looking for a name, have bought rompers, organized the pram. But overnight, totally different, existential questions come to the fore: Will my baby develop well, how long does he have to stay in the clinic? In Germany, every tenth baby is born prematurely; which means that the baby was born before the 37th week of pregnancy with a birth weight below 2500 g. Thanks to the enormous progress of medicine, the chances of survival and development of preemies are today better than ever before.

That’s a big success of medical care and nursing. Day and night pediatricians and nurses are attending to the well-being of the smallest patients. Despite the incubator and the cables and wires, they try to make their premature start to life as natural as possible. However, the first time after the birth remains nerve-racking and energy sapping for both the children and their families.

For weeks, sometimes months the parents spend every free moment in the hospital, always anxious about their child’s health. What appears to be more fragile than a baby in an incubator? The small fist not much bigger than a walnut, the tiny body connected to tubes and wires allowing the baby to survive outside the mother’s womb. In this difficult time the parents need professional help and personal accompaniment. But even after discharge from the clinic, many questions and sorrows related to everyday life at home remain open.

I therefore appreciate the commitment of the Federal Association “Das frühgeborene Kind” e.V. This association helps concerned parents and relatives with support groups, information material and congresses. This brochure gives valuable hints and tips and I would like to thank all persons involved.

Ulla Schmidt
Foreword
by Silke Mader, President of the Federal Association “Das frühgeborene Kind” e.V.

“What should I name my child? Is the nursery ready furnished? How long do I want to go on parental leave?” Questions that parents ask themselves over and over again.

Questions, however, to which parents of preemies haven’t found any answer yet, because their baby was born much too early and other questions have become much more urgent such as: “Does my child in the incubator know that I am there? How can I establish contact with him?” or “Why is the monitor always beeping?”

“Can I actually breastfeed my baby?” Questions and more questions; problems piling up like mountain. When a child is born prematurely, parents are often completely helpless and without information in face of this new situation. We, the umbrella organization for parents self-help of preterm infants, know from own, sometimes painful experience how important it is to get an answer to these questions as quickly as possible. And we would like to give you answers to all your urgent questions.

Thanks to a sponsorship by Abbott GmbH & Co. KG we can provide you, dear parents, with these information in a starter kit. Our association has prepared various publications giving you comprehensive information on individual topics. In the rear part of the brochure you will find an overview. In case there is no flyer of the location group in the starter kit bag, you can find the contact details of the regional self-help groups on our homepage under www.fruehgeborene.de. Both the regional groups and we as the umbrella organization will support you if you have any questions.

We wish you and your child/your children all the best and strength in the coming weeks and months.

Your Silke Mader
The neonatological intensive care unit - a preemie's first home

(Condensed version from “Premature babies – advice and support for concerned parents”)  

Prof. Dr. Gerhard Jorch, Magdeburg University Hospital

Premature babies needing respiratory or circulatory assistance after birth are treated in a neonatological intensive care unit. Premature babies dependent only on heat supply, stomach tube or infusion together with permanent monitoring, lie in a neonatological intensive monitoring unit. You will find these two forms of treatment in every premature baby centre - but they have different designations. In this article we will call them Neo 1 and Neo 2. A Neo 1 usually has got 4–16 beds. There is shift work of the medical and nursing staff, which means that nurses and doctors are present around the clock. A treatment place consists of:

- Intensive incubator or intensive warming bed
- Monitor for ECG, respiration, oxygen saturation, temperature, blood pressure measurement and other data
- Precision infusion instruments
- Respirator and other apparatus for ventilatory support
- Other equipment such as evacuators, pleural drainage systems, spot lighting for interventions, disinfectant dispensers etc.

There is usually one nurse for 1-3 patients, one doctor for 4-12 patients.

A Neo 2 usually has got 12–24 beds. There is shift work of the nursing staff and a medical on-call duty, which means that the doctor is available within a few minutes. A treatment place consists of:

- Intensive incubator or intensive warming bed
- Monitor for ECG, respiration, oxygen saturation, temperature, blood pressure measurement and other data
- Precision infusion instruments
- Other equipment such as evacuators, spotlighting for interventions, disinfectant dispensers etc.
There is usually one nurse for 3-6 patients, one doctor for 12-24 patients. In principle, parents and close relatives have access to the wards at any time, but with regard to the other patients there are usually certain rules as to the main visiting hours. Parents have comfortable armchairs, rocking chairs or couches to allow them cuddling with their child (the so-called kangaroo mother care). The aim is to get the parents as much as possible involved with their children’s care. At best, they can feel like a member of the treatment team.

Below we have tried to explain the most important apparatus, devices, measures and drugs.

**Incubator**
A closed transparent container with precisely controllable inside temperature, air humidity and (if necessary) oxygen content for technical nursing of very immature preemies and/or preemies needing intensive care treatment. Nurses, doctors and parents can have access via lateral flaps. The incubator is supposed to ensure the care of the undressed and thus easily accessible premature baby without heat and fluid loss. Careful attention must be paid to avoid bacterial contamination of the interior as far as possible. Alarms ensure the observance of temperature, humidity and oxygen concentration.

**Warming bed**
In a warming bed are treated preemies showing better temperature stability yet. In this also box-shaped and transparent bed the child is accessible from above through flaps. Heat can be introduced by means of a heatable mattress and through a heat radiator from above. The air humidity is not controlled. For the most part the children are dressed. There is alarm function, too.

**Monitor**
This apparatus records ECG curve, respiratory curve, oxygen saturation, and other data. Alarm functions indicate when a value exceeds or falls below a set measurement limit. For parents, nurses and doctors it is, however, important to look primarily at the child instead of focussing too much on the monitors. Most alarms are false alarms!
Infusion pump

These instruments help to administer infusion solutions and drugs extremely precisely. They can be fine-adjusted up to 1 drop per 30 min. (!). Since almost always several infusions have to be administered simultaneously, various precision pumps are required per treatment place which are placed most of the time like a “tower” in a rack. The purchase price for such a tower is - like for an incubator or a respirator - within the price range of a compact car. Since, during a preemie’s treatment, the infusion speed has to be readjusted many hundred times and the respective setting can be vitally important, the nurses’ responsibility who are manipulating these apparatus cannot be appreciated highly enough. However, there are alarm functions to assist the nurses.

Ventilation

When the child is too weak to breathe sufficiently due to an immature lung, he has to be mechanically ventilated until the pulmonary function has improved. This is done through fine-tuned inflation of the lung with 10 to 80 breaths per minute. Expiration is made by means of the elastic restoring force of the lung and the thorax. In order not to further impair the already immature or diseased lung, inspiration time and pressure curve have to be precisely adjusted. In addition, they try to allow the child to breathe a little on his own to train his
respiratory muscles and make mechanical ventilation more bearable. An optimal humidification and warming of respiratory gases is also vital. Proper ventilation is a high art and will be mastered only after having been practising for quite a long time in an intensive care unit. In special cases high-frequency ventilation is used. In this technique, the thorax is vibrated with a frequency of approximately 10 breaths per second in order to allow the uptake of oxygen and disposal of carbon dioxide. Both forms of mechanical ventilation require a previous “endotracheal intubation”, which means that a plastic tube with a diameter corresponding to the patient’s little finger is introduced into the nose or mouth and directed to the trachea.

**CPAP (“Continuous Positive Airway Pressure”)**

In this method of ventilatory support the patient breathes by himself. However, his lungs are continually inflated at a pressure of 3-8 cm of water column. For physical reasons, this alleviates breathing and prevents lungs from collapsing. Preferably, the inflating pressure is applied through two plastic tubes that are introduced into the nasal passages (“nasal CPAP”). An intubation is thus not necessarily required.

**Nutrition**

It is basically sought that premature infants, too, start taking the bottle or breastfeeding as early as possible. Anyhow, they often have to be fed for a longer time through a stomach tube with milk or even with infusions of specially prepared nutrient solutions. The stomach tube is introduced through either mouth or nose directly into the stomach, the infusion is administered via tiny plastic cannulas into peripheral veins (peripheral venous cannula = PVC) or super-thin plastic tubes (central venous catheters = CVC) into the large afferent veins directly in front of the heart. Although the total daily amount of food (milk into the stomach and/or nutrient solution into the veins) administered to preemies is up to one fifth of their body weight, this is for a preemie weighing 1000g only 8 x 25 ml of milk or 3 drops per minute of infusion solution!

**Examinations**

In the physical examination of preterm babies the observation is unlike in adults more important than the assessment of findings through
palpation, auscultation or triggering of reflexes. Ultrasound (the “pediatrician’s third hand”) plays also an important role, allowing to represent in cross sections without substantial adverse effects and without risk not only the brain, the heart, the kidneys, and the abdominal organs (ultrasonography), but even to visualize and measure bloodstreams (Doppler ultrasonography). X-ray pictures can be taken from the child lying in the incubator through mobile x-ray units, but this method is only restraintedly used because of the radiation exposure. However, for the evaluation especially of the immature lungs and the recognition of complications in ventilation therapy this method is still very important.

Drugs

Various drugs have already to be administered to preterm infants. We will only mention here some of the most important. Surfactant is administered after the birth directly into the trachea via the respiration tube or a probe. From here it is pushed into the alveoli, expands them and keeps them open in order to accelerate withdrawal from mechanical ventilation or to actually make it unnecessary. Antibiotics (penicillin, cephalosporin etc.) are vital to fight bacteria which have penetrated the body and thus to avoid life-threatening infections. In most cases, they are administered via cannulas and catheters into the blood vessels, just as catecholamines (dopamine, epinephrine etc.) which stimulate the circulatory system. Caffeine (active ingredient of coffee) and theophylline (active ingredient of black tea) stimulate the respiratory activity and stabilize spontaneous breathing after withdrawal from mechanical ventilation.

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Breastfeeding a preterm infant

by Erika Nehlsen, IBCLC (International Board Certified Lactation Consultant), Training centre for lactation and breastfeeding, Ottenstein

At present, you are certainly worrying because your baby was in a bit of a hurry to be born. Now he is in hospital in the neonatal intensive care unit and still needs special medical attention to help him compensate his premature start.

You can assist your baby in his adaptation and maturation process by spending a lot of time with him, giving him back some of the closeness which he actually would still have been experiencing for some time and which he now especially needs by providing him skin-to-skin contact (kangaroo mother care = naked parents’ skin to naked baby’s skin).

You, dear mother, have in addition the marvellous possibility of giving breast milk to your baby. The breast milk of women after a preterm delivery is especially adapted to the needs of their baby; it contains more proteins and also more antibodies against germs.

Not every woman has planned before delivery to breastfeed her baby. I would like to encourage you to start breastfeeding, though. You might set yourself short-term targets first; perhaps you decide later to go on if you like it and you can see your baby benefiting from your milk:

- Pump your milk until the baby is stable
- Or pump until the baby is discharged
- Breastfeed your baby as soon as he is allowed to be put to the breast

Spend a lot of time with your baby; see how your baby enjoys being close to your breast during kangarooing. Your nipples and areolas are especially rich in mother’s scents. Your baby can recognize you by your individual scent which is already familiar to him from the time in the womb.

The mother-infant contact during the first hour after birth is associated with higher breastfeeding rates and longer breastfeeding duration. The skin contact between mother and child increases the amount of milk, the breastfeeding duration and the success of breastfeeding.
Breast milk has especially in premature babies further medical advantages:

**Gastrointestinal tract and thriving**

- Quicker stomach emptying
- More stable intestinal mucosa; breast milk supports the development of a useful intestinal flora; the especially rich immune substances of the preterm milk (milk of the mother of a premature infant) line the bowel like wallpaper or a protective coating and thus prevent the transmission of microorganisms and antigens (substances that trigger diseases).
- Less stomach remnants at the next meal
- Breast milk is tolerated well by the infant
- The laxative effect and the digestive enzymes, which “pre-digest” the breast milk are especially important for the immature digestive system of a premature infant
- Faster achievement of full oral nutrition
- Stimulation of growth, maturation and peristaltic movement of the bowel
- Enzymes that help the preterm infant to better absorb and utilize nutrients
- Improved food intake and utilization, even when special preterm formula has to be added to the breast milk

**Protection against infections**

- Rarer occurrence of serious bacterial infections (septicemia)
- Less urinary tract infections
- Reduced risk of necrotising enterocolitis (NEC) and other intestinal infections
- Babies born prematurely miss out on the transplacental delivery of calcium, iron and immunoglobulins that occurs during the third trimester of gestation. The only way premature infants can receive the infection fighting immunoglobulins is via breast milk.

**Other advantages of breastfeeding/feeding breast milk:**

- Lower renal solute load through balanced composition
- Better development of intelligence: breast milk improves visual development and intellectual development in preterm infants
Fewer retinopathies (disease of the retina in preterm infants)
Fewer complex therapies (antibiotics, surgeries)
On average, the hospital stay of preterm infants receiving breast milk is 14 days shorter

It would be perfect if you could start short after birth emptying your breasts and produce the precious colostrum (pre-milk fluid produced during the first days after birth). Colostrum only comes in low quantities; it contains antibodies against all the germs you came into contact with during pregnancy offering an initial immunization to your baby.

A baby born at term or nearly at term mostly already starts sucking at the breast within the first hour of his life in the maternity room. If you can manage to have your colostrum at your baby within four hours by emptying your breast, your breast milk can often be the first nutrition. Besides the concentrated antibodies, your colostrum has the precious property of stimulating the bowel movement so that the first stool of your baby is passed more easily.

In addition, colostrum and breast milk contain a number of digestive aids which help your baby digest the milk without having to spend much energy.

You can manually express the colostrum and collect it into a small sterile syringe. A sterile plug ensures safe transportation of this precious first milk to your baby. In many hospitals the father brings the first colostrum to his baby.

In order to facilitate and encourage breast milk supply, you, dear mom, have to stimulate and empty your breasts as often as a maturely born infant would normally do. Kangaroo care increases the physical stability of your baby, gives him a sense of security, to be with his mother again and encourages the hormone-based supply of milk.

During the first 8 to 10 days after birth, the breasts are getting “adjusted” to their “basic function” for this nursing period/this baby (or even several children). Under the influence of high prolactin values it is possible to increase the amount of milk by regular and sufficient pumping (at least 6 to 8 times/day, including 1 to 2 times at night). From the third day, a mature baby would probably breastfeed even more often. During the first days after birth, when you are still in hospital and are well accommodated, you should keep this frequent manual emptying/pumping in order to quickly obtain large amounts of milk.
During the first two days emptying is made manually at first and then by pumping, because expressing by hand allows better collection of the small but very precious amounts of colostrum. Colostrum is more viscous and pasty and would stick to the walls of the pump bottle making thus the administration to your child difficult.
It’s normal if on the second day there is a little less milk; the colostrum you have been producing during your pregnancy already, runs short and active lactation starts. On the third day already, you will see that your milk gradually begins to increase.
You will need sufficient instruction/advice and a good electric breast pump (Medela Symphony or Ameda Elite).
The more milk you pump, the more milk your breasts produce. If you don’t want/can’t use a double pump kit, you should change the sides frequently in order to trigger the milk ejection reflex (MER).
Pumping is not always easy. However, regular pumping to stimulate the breasts is essential for sufficient milk supply. When you are pumping at your baby’s bed or next to it, you will often have more milk. Likewise, when you can listen to relaxing music while pumping.
Careful hand washing and sterile/disinfected pump kit/bottles is a prerequisite for getting milk with a germ content as low as possible. Bags should not be used, because the milk cannot be decanted without risk of contamination. If possible, wash your breasts under running water before pumping and always use a fresh breast pad. Take a shower once a day, if possible. Once the abundant milk supply has started, you should first hand express a few drops of milk and throw them away for reasons of hygiene. The milk should preferably be fed raw, because pasteurization destroys the lipase in breast milk and therefore impedes fat digestion reducing thus the calorific value of breast milk.
Although the baby needs much less milk in the beginning, you have to achieve a sufficient amount of milk in the first time, because later, when your baby quickly needs larger amounts of milk, it is more difficult to increase the amount if no sufficient “initial adjustment” was achieved during the first days under the influence of prolactin.
If you have multiples, you have to pump at high frequency after birth until you achieve about 500-600 ml/day per child.
It would be perfect if you could achieve at the end of your baby’s first week of life about 500-600 ml within 24 hours. From around the tenth day after birth the prolactin level gradually starts decreasing and from the sixth week after birth it is not as easy to increase the amount of milk. Therefore it is recommended to frequently empty the breasts during the first eight to ten days already in order to get an amount of milk a maturely newborn baby would need.
The milk should be immediately refrigerated in a closed, labelled (name, date, time) container. Milk that is not fed fresh must be frozen as early as possible. Breast milk for preterm babies can be kept at room temperature for 4 hours, for 72 hours in the fridge at the BACK, NOT in the door! Thawed breast milk has to be fed within 24 hours.

Pumping, storage and transport of mother’s milk

- Ask the staff to show you the technique of milk expression (by hand, with electric breast pump)
- Ask your doctor to give you a prescription for an interval-controlled piston pump (with double pumping set!)
- Ask for written guidelines for milk expression and storage/transport
- Pumping for weeks and months can be frustrating – Don’t lose heart! Talk to other mothers in a similar situation (association for premature infants, breastfeeding support group)

Once you have achieved an abundant milk supply, you can try to manage with less pumping. This depends on your individual breasts. Try out, by gradually extending the intervals between pumping, if you can achieve the same daily milk amount. If, for example, you have pumped every three hours 100 ml, you can pump every four hours if you manage to achieve 130 ml in this way. With one baby you should

Breastfeeding serves not only nutritional purposes, but also satisfies the need for closeness.
try to achieve a rate of milk production of 30-35 ml/hour. (For twins it is double the amount, for triples triple the amount etc.). If the amount per hour decreases, the pumping intervals have to be shorter until this milk amount/hour is achieved again. Whereas the amount of milk can be increased to be enough also for twins and triples, it depends on the woman how much pumping is to be done for this.

In the beginning, as long as your baby only needs minimal amounts, you possibly want to freeze the excess milk. This gives you also security if there should be any temporary drops in your milk supply during the time your baby stays in hospital.

As soon as you have achieved an abundant milk supply and your baby does not yet need the whole amount, you maybe want to pump the first half of your milk in a bottle and the second half in another bottle. The bottles have to be marked accordingly. The second half of your milk contains more fat. This allows your baby to have several times a day the more fat containing hindmilk and to gain thus more weight. The long-chain polyunsaturated fatty acids in the fat aid the maturation of your baby’s brain, his vision and prevent the appearance of allergies.

With an adequate nutrition with fatty sea fish twice a week and rapeseed oil, for instance, for your salads, you make sure that you have a large amount of these special fats in your milk. A balanced diet is advantageous for you, too.

Although the amount of vitamins, minerals and trace elements in the breast milk is hardly influenced by the nutrition - you will produce good milk even though you eat a lot of ‘junk food’ - your physical and emotional wellbeing will be better if you eat more healthy food.

After discharge from the clinic, your daily routine will be more time consuming for some time, because you have to take care of yourself, pump regularly and want to spend time with your baby. During this time it is essential to receive good support from your partner, your family and friends.

The doctors and nursing staff who take care of you during this time often believe that pumping causes you additional stress and consumes your power.

From a scientific study we know: Mothers see this different; they say that providing breast milk especially to an ill or very prematurely born child often was the only relationship with their baby.

Women who have managed to breastfeed their preterm infant mentioned the following 5 points to be particularly satisfactory:

- the knowledge to provide the healthiest, best food
- to reinforce the bond with the child
to notice how breastfeeding calms the baby and keeps him satisfied
comfort for you and your family
having a legitimate claim on your baby, by giving him something no one else can do

Preferably during your stay in hospital already you should be given a recipe for a good electric breast pump with double pumping set. Double pumping sets have the advantage that you can save a lot of time while pumping. They reduce the pumping time to half and cause an increase in prolactin level which is important for milk supply.

You, dear dad, should have organized this breast pump already before your wife’s discharge from hospital so that everything is prepared. Don’t hesitate to accept offers to help you for shopping, doing the laundry, ironing; let others cook for you. This all will help you to overcome the challenging time with a baby in the hospital where you should spend a lot of time and do kangaroo care.

That’s something only you can do for your baby: giving him a feeling of security, love and protection through body contact (kangarooing) and breast milk.

The mother should spend as much time as possible with/next to her baby. She will then take up the germs in the premature baby unit into her body. The mother’s lymphatic system will then build antibodies against the germs her baby is also exposed to in the premature baby unit. Specific immunoglobulins (proteins manufactured in the body to fight against foreign substances, called antibodies) against these germs pass into the breast milk protecting the baby against the germs he is exposed to in the clinic.

**Premature babies during the first weeks of life**

This brochure can help those concerned and interested to get an idea of the developmental conditions of preterm babies and of the possible aids. The abundance of problems touched shall help to provide comprehensive information to be able to prepare adequately for the stressful individual situation. The following topics are approached:

- Causes of premature birth
- Chances and risks of premature infants
- Neonatal intensive care units (NICUs)
- The NICU as development environment
- Initiation of parent-infant relationship

Helps for the baby and his parents

This brochure and others about premature infants can be ordered from the Federal Association under the link “Publikationen” at: [www.fruehgeborene.de](http://www.fruehgeborene.de)
If the supply of your breast milk declines significantly (occurs often if there are problems with your preemie or at home) the following factors have to be excluded which affect the amount of milk:

- Infrequent pumping
- Breasts not sufficiently emptied/pumping not long enough, MER not triggered
- Exhaustion, fear, stress (e.g. if the baby is not doing well)
- Drugs such as antihistamines, bromocriptine, estrogens
- Mother’s serious illness
- Increased activities at home

The following measures are helpful to increase the amount of milk:

- Relax 10-15 minutes before pumping
- Massage your breasts with circular movement, before pumping and in between back rub of the mother before and during pumping, especially between the shoulder blades
- Have a warm drink
- Pump more often
- Continue pumping for 2 minutes after the milk has stopped flowing
- Look at a picture of your baby
- Take a smell at a worn clothing/pad of the baby
- Pump next to the baby or directly after kangaroo care
- Pump in a calm and relaxing environment with dimmed light
- Listen to relaxing music while pumping
- Think of flowing water, a waterfall, waves in the sea and visualize this
- Balanced nutrition and drinking sufficient amounts of liquids
- Smoking reduces milk production, preferably completely quit smoking; if this is not possible, reduce smoking and change to a cigarette with less nicotine

Everything that assists the milk ejection reflex is helpful. Without the MER only 4% of the available milk can be expressed. During crisis you can temporarily also use Syntocinon spray.
If you were not able to sufficiently stimulate milk production after the birth, the milk slowly decreases due to a lack of information/support or because you didn’t plan to breastfeed, the milk production can be increased with drugs (Metoclopramide, Domperidone) if frequent emptying of the breasts alone is insufficient to stimulate milk supply. These drugs are only available on prescription and can only increase the amount of milk together with sufficient frequent emptying of the breasts.

If you spend a lot of time with your baby, you will quickly get to know him and can, under the guidance of the nursing staff, participate – at least in parts - in the care of your baby according to his rhythm.

There should be a regular “briefing” as often as necessary between you and the nursing staff, in order to find a joint mode of communication and care for you and your baby adjusted to your baby’s condition and your possibilities. It’s important that you also talk about your feelings and thoughts. Only when mothers communicate, it is possible to adapt to each other.

Kangaroo care is the first step to successfully breastfeed your premature baby. Adjust your everyday life to the fact that your youngest child needs you most now. Kangarooing only makes sense if you can spend at least 1 hour with him (organize help at home!). More time is better. Mother/parents and baby can practice kangaroo care as long as they want and the baby is in stable condition. You can already begin kangaroo care even if your baby is still ventilated. The skin contact (mom’s naked skin to baby’s naked skin) is very important. You should take off your bra, because there are great many mother-specific scents released in the area around the nipple/areola that the baby still remembers from his time inside the mother’s womb giving him a better feeling of security. A preemie having skin contact has a more stable respiration, heartbeat and body temperature control and a better peripheral oxygen saturation than preterm babies without skin contact. Kangarooed babies gain weight faster, sleep more and...
cry less/have less stress. Kangaroo care helps the baby and helps you overcome the separation which occurred too early and establish an affectionate relationship. It will help you maintain your milk supply. Caressing massage of your baby (with the finger tips always in the direction of hair growth) from head to feet, from the backbone to the fingertips, assists the growth and maturation of the preterm infant and is relaxing for both of you.

You will feel more comfortable if you don’t have to be completely bare while kangarooing your baby. You can wear an unbuttonable blouse or jacket and partially close it over the baby to protect you from curious eyes. If you tuck it into the waistband of your skirt/pants, you can also be sure that your baby will not slip off, even if you doze off while kangarooing.

Depending on the maturity, very prematurely born children are for the most part tube-fed at the beginning. In this case, they should always be given the chance of sucking on something. This can be the father’s little finger or another sucking object. If you, dear mom, are present, tube-feeding is supposed to be made while your baby is on your breast. Your preemie will then learn to associate mouth activity with satiety. An important learning success for his whole life.

Even if your baby is not yet allowed to be fed through the mouth, you can already start mouth care with breast milk. This assists already the maturation of the immune system of your premature baby and helps colonize him with beneficial germs as well as stimulate the digestive functions and gut motility.

To “practice”, your baby may also be put to the breast. If you have a lot of milk, you can pump before latching on so that your baby doesn’t get overwhelmed with the milk flow.

There are signs that a premature infant is ready to breastfeed. For a long time it has been assumed that it is easier to drink from the bottle than from the breast. In the meantime, studies and observations have shown that breastfeeding is more physiological and easier than bottle feeding. Heartbeat, respiration, peripheral oxygen saturation and body temperature of the breastfeeding preterm infant are more stable than on the bottle. Apnoeas and bradycardias (slow heart rates) occur less often. Breastfeeding can already be started before the premature infant can drink from the bottle.

At 28–30 weeks of gestation many babies can coordinate breathing, sucking and swallowing and can be put to the breast for “practicing”. The ability to breastfeed varies from baby to baby. However, there are some hints:
Approximately at around 30 weeks of gestational age  
Hand-to-mouth activity  
Can breathe on his own  
Sucks on the tube or another sucking object  
Search reflex exists, readiness to latch on  
Tolerates bolus feeding  
Baby can maintain his temperature outside the incubator at the mother’s body  
Seems to need more sucking satisfaction  
Swallows his saliva

If your baby shows two or more of these signs, he is ready to make his first breastfeeding experience. Most of the time, the first attempts at breastfeeding are licking, cuddling and becoming familiar with the breasts. Do not expect your baby drinking a measurable amount of milk from the breast. But it is crucial that your baby becomes familiar with the necessary oral activity on the breast and can breastfeed before you can start with bottle feeding that requires a different oral motor control.

Do not take a shower or wash your breasts shortly before breastfeeding. The pheromones in the area around the nipple and areola raise the baby’s interest in the breast. Signs that your baby is ready to breastfeed are:

Awake alertness  
Oral activity: licking, smacking, extending the tongue  
Hand-to-mouth-activity, trying to suck his fingers  
Body movements

Once the baby has started crying, it’s too late. Crying babies cannot seize the breast well.

To begin breastfeeding, you and your baby need a calm, comfortable place. The instruction and help of the staff to find the right breastfeeding position for the baby and to latch on well are necessary as soon as the baby shows signs of being ready for breastfeeding. Patience is a precondition for everyone involved. Breastfeeding techniques for premature babies don’t differ significantly from those for maturely born children. They have to be well positioned and well supported (ear, shoulder and hip should be in a straight line, the mouth at nipple height); the football hold or cross-cradle hold is recommended. Arms and legs of the baby must be “collected” and must not
hang down. The ball of your thumb should be between your baby’s shoulder blades supporting his head with your fingers. Babies should not be touched at the back of their head; many of them will writhe and cannot breastfeed. Babies with dysphagia probably drink better when they are well supported and held upright in saddle hold.

You can express some milk by hand and assist the milk ejection reflex to facilitate milk flow. If the baby does not go to the breast within 5 minutes, do not make any further attempts, change to kangaroo care, and feed your baby differently. As soon as the baby is getting more attentive after some time, try again; help your baby latch on.

By and by your preemie will learn to breastfeed more effectively, and then you can weigh him before and after breastfeeding in order to find out how much has still to be fed through the feeding tube. You should breastfeed at every visit, if possible several successive breastfeeding sessions. Supplemental feeding of the baby at the breast has turned out to be the best way to achieve a satisfying development of weight gain and successful breastfeeding.

Signs of a good breastfeeding session are slow and deep gulps, followed by swallowing over several minutes. If your baby takes a break of more than 15 seconds, stimulate milk flow by compressing the breast; to make the baby more attentive, you can massage the baby, talk to him or switch him to the other breast; do whatever brings your baby to continue drinking actively at the breast.

Preparing for discharge to home

You have to be familiar with taking care of your baby 24 hours. You should have 24h rooming in with your baby at least during the last few days before discharge. You know that you have to nurse your baby every 2-3 hours around the clock. Breastfeeding on demand is possible. In case your baby doesn’t nurse often enough, you must wake him up. You should at least master one more feeding technique if your baby cannot be woken up.

You should continue kangarooing at lot with your baby. Some meals will go well, some will be troublesome. Compressing your breasts helps your baby to take more milk. If he doesn’t drink well during the first 10-20 minutes, you should practice supplemental feeding, preferably on the breast. If your baby isn’t fully breastfed yet at discharge, the prescription for the breast pump has to be renewed. You should be able to return to the premature baby unit or call them.
whenever problems with the baby occur. A good follow-up care at home (lactation consultant) should be ensured. Make an appointment for the follow-up visit.

At home
Organize help in the household (preferably around the clock), because at the beginning you will only be able to care for yourself and for your baby (frequent latching on day and night, a lot of skin contact and carrying). A baby sling or pouch and a comfortable rocking chair can be helpful. Babies who have a lot of skin contact and are carried or rocked often thrive better.
Your baby should have 6-8 wet diapers/day and 3-4 bowel movements a day.

Premature babies do very well with finger feeding, cup feeding and supplemental feeding on the breast. Babies getting supplemental feeding in this way have bigger chances to be still breastfed 3 months after discharge than babies with supplemental feeding from the bottle. A close monitoring by a lactation professional, midwife and pediatrician is required.

You are now taking with your baby the first steps into the adventure of life. Regardless of how much you know, it’s normal that a number of questions will turn up when you start nursing your baby. This guide is intended to provide you quickly with information. It shall help answer your questions, explain the basics of breastfeeding, prevent the occurrence of difficulties in breastfeeding and make suggestions what you can do if difficulties still arise. Don’t hesitate to ask the staff in the pediatric clinic or lactation professionals near you if something remains unclear.

Warmest regards and best wishes for the future of your baby!

**Information**
www.stillen.de
www.neonatalbegleitung.de
info@stillen.de

**Literature for parents**
“Geborgenheit, Liebe und Muttermilch” F. Egli/K. Frischknecht, 2002, self-published, available from Ausbildungszentrum für Laktation und Stillen, Kantor-Rose-Str. 9, D-31868 Ottenstein
“Stillen von Frühgeborenen” G. Gotsch, La Leche Liga Deutschland, 2001
Practical help after a premature birth

Cert. social pedagogue Carola Weber

In most cases a premature birth is a sudden and unexpected situation which you could not prepare for sufficiently. To help you manage better the daily up and down between joy, hope, sorrow, care and bureaucratic procedures, I would like to give you below some hints which may facilitate your hospital stay.

Arrival to the ward

In the meanwhile, many wards provide the parents with brochures containing all important information on the routine, contact persons and phone numbers of the ward, pump and parents’ rooms, parent accommodation, possibilities of visiting for siblings and relatives, childcare as well as available parking and catering.

As parents you have possibilities and rights:

- You can call the ward at any time and inquire about your baby’s condition.
- You have the right to be informed on the health condition of your baby and of the therapeutic measures.
- You can request at any time to talk to the competent doctor. In most cases, an appointment will be made shortly. In some wards the senior physicians have special consultation hours.
- Ask for details if you didn’t understand medical terms or contexts. The nurses and doctors will be pleased to explain you the situation using understandable terms!
- Visits are welcome, but not too many persons at once, because this will be too stressful for your child and the other children in the ward.
- Many wards allow siblings to come visit the new family member, if necessary after having been examined first.
- Maybe there is even a possibility of staying overnight in the parents’ room or in a special parent’s accommodation of the clinic.
You can do a lot to establish a bond with your child:

- Visit your baby as often as you can. Mom and dad are irreplaceable and at least as important as the best medicine!
- Talk or sing with your child to let him hear your familiar voice.
- Create your own welcome and goodbye ritual to give you and your child security.
- Extensive touching (hand around the head, hand to the back/belly, hand under the foot soles), kangaroo care and cuddling are very special and precious moments for you and your child.
- Depending on the health and condition, the staff nurses will as soon as possible introduce you to and involve you in the nursing and kangaroo care of your baby.
- Your child will love his own cuddle cloths and soft toys. Discuss with the nurses when you can bring his own clothing.
- Photos of siblings, religious symbols or the like can be fixed to the child’s incubator/bed in arrangement with the nurses.
- Filming or taking photographs is possible if it has been discussed with the nurses.
- Only inform yourself to an extent that does you good! Not every information you find on the web or in books will help you!
- And first of all: Take care of yourself! Regain your strength in between, because your strength and calmness will be transferred to your baby and help him develop!

What is to be done soon?

**Apply for the birth certificate**

Some clinics take on the registration of the newborn child at the Register Office and organize the sending of the birth certificates. In other clinics the parents have to do it themselves. Registration of the newborn must be made within one week.

You get free birth certificates to apply for parental allowance and child benefits, to apply for health insurance as well as for religious purposes. Your clinic will give you the contact details of the competent Register Office.
**Application for the child’s health insurance**

In most cases, a phone call of the mother or the father to the health insurance company is enough. They will send you the application form for a family insurance to your home. In case you want to have a private (additional) health insurance policy for your newborn, you should decide quickly, because the period in which no evidence of insurability is made, is only a few weeks.

**Information of the mother’s employer**

Informing him by phone is sufficient for the time being.

**Unemployment benefit recipients**

You are obliged to inform the competent employment office of your child’s birth. If need be, you can apply there for the financing of a layette kit.

**Interval breast pump**

You will get breast pumps at the chemist shop. On presentation of a prescription from the gynaecologist, the pediatrician or your family doctor, your health insurer bears the expenses.
Unmarried couples/single parents

The child custody arrangement and the acknowledgement of paternity are to be made at the youth welfare office. Single parents have in addition the possibility of applying for an “official assistance”.

What can wait a little?

Application for maternity benefit

You will get the application form for maternity benefit from your health insurance company.

Application for child benefit

You can get the application form from the town hall/community centre/district office which can only be submitted after having received the birth certificate. You can also download the application form at the following web address respectively the following link: http://www.arbeitsagentur.de – Formulare – Formulare für Bürgerinnen & Bürger – Kindergeld

Application for parental allowance

You can get the application form for parental allowance also from the town hall/community centre/district office. Each federal state has its own office for parental allowance which you can find on the web.

Possible assistance:

During hospital stay:
- Pastor
- Psychologist
- Social pedagogue, social service professional
- Parent counselling
- Home help to look after the household and siblings; this requires a medical certificate

After discharge:
- Midwife
- Sociomedical follow-up care
- Socialpediatric centre
- Early intervention
- Family counselling centres
- Family helper
Literature, associations and self-support groups

You will get information from
Bundesverband “Das frühgeborene Kind” e.V.
Speyerer Straße 5
760327 Frankfurt am Main
Information line (01805) 87 58 77 (0.14 Euros/min.)
Tue. and wed. 9:00–12:00 a.m.
Fax (069) 58700999
Email info@fruehgeborene.de
Web www.fruehgeborene.de

Family and friends

Relatives, friends and neighbours can be a great help. They often support the family in the household work such as doing the laundry, grooming, doing shopping or looking after the siblings. Don’t hesitate to accept their help. But often family and friends are themselves overstrained with the situation “premature birth” and don’t know how to behave towards you. Perhaps you could use a “messenger” to regularly inform your personal environment. In most cases family and friends feel relieved if you as parents tell them which kind of support you need concretely and what does you good!

We wish you and your family strength and all the best for the forthcoming period!
Development of relationship and bond between parents and their premature babies

Cert. psychologist Susanne Hommel, Altona Children’s Hospital, Hamburg

Giving birth prematurely is for all parents an emotionally very unsettling event. The initial separation from the child is hard for all parents. In most cases, the mothers are discharged from the clinic a few days after birth and have to leave their child there. This is directly after a child’s birth a situation which seems to be nearly insupportable. Many clinics have abolished formal visiting hours in order to allow the parents to satisfy their need for closeness with their child without any restrictions. They involve the parents into the care of their child as soon as the baby’s health state allows it. Besides the concern for the wellbeing of your child, you will probably worry about how to establish contact and develop a relationship with your daughter or your son. You as parents are the most important person to relate to. Even if your child was born too soon and requires intensive medical care treatment, there are many ways to establish already contact with your child, to attend to him and take care of him.

Be there for your child

Be there for your child is the best you can do to support his development. Don’t get discouraged if you find your child at the beginning most of the time asleep. Especially very small premature babies need extremely much sleep, because they are growing and thriving while sleeping. Initially they can only be awake and alert for a very short time. In addition, the sleep-awake phases in premature children are difficultly predictable at the beginning. However, the care periods dictated by nursing allow finding out a rhythm that you as parents can prepare for in order to be there for their child.

Breast milk is precious for a healthy development

Breast milk is more than only the best way to nourish your child. Providing your child with breast milk every day perhaps seems to you to be only little support in view of a small child in need of protection and care, but it is a decisive contribution to his healthy development. Most neonatal intensive care units have especially trained breastfeeding and lactation consultants who will be pleased to answer your questions about how to manage pumping the breast milk, breastfeeding attempts and later breastfeeding.
Feeding means more than only nutrition

Feeding your child will consume a lot of your time due to the frequent meals. Feeding means also closeness, contact, care and implies different sensory experiences such as flavour, smell and touch. It depends on the health condition and kind of nutrition how much you can be involved in feeding your child – discuss this with the nursing staff.

Your familiar voice calms your child

Especially very small premature babies have to spend often many weeks in the protective environment of the incubator until they are stable enough to be put onto your breast (so-called kangaroo care). Even premature babies are already familiar with the voice of the mother or the father from the time in the womb. The sound of your voice communicates to your child the feeling of security and love and has a calming effect. You should therefore talk to your child, read or sing to him when you are with him. You can also create a cassette tape that can be played for your child while you are away.

Premature babies after discharge

In the clinic the preemie has been taken care of 24 hours, now he comes home. Many parents don’t feel well prepared for the time after discharge to home. This brochure is intended to help explain concerned parents the specific characteristics of premature babies and how they can learn to manage this. This and further brochures about premature babies can be ordered from the Federal Association under “Publikationen” at: www.fruehgeborene.de
Touching is important for your relationship

Touching and body contact are important for the relationship between parents and child, even though premature babies appear very petite and fragile in the beginning. Many parents are afraid they could overstrain their child or even harm him by their own clumsiness. As parents you should trust your feelings and determine the moment and the intensity of touching. You may want to get to know your baby slowly. If you want to take more time for this than other parents do, that’s perfectly ok. Premature infants are easily irritable unlike maturely born infants. They are not yet able to cope with quickly changing touching in different body regions and caressing movements. You should therefore touch your child calmly and slowly with the whole palm of your hand. Especially holding the head or feet of the little ones seems to give them a pleasant feeling of security which they visibly enjoy. You should avoid knocking on the incubator, because noise from outside is reinforced inside the incubator and perceived by the children as unpleasantly loud.

Don’t feel unsure if your child is very restless during the first contact. After all, this situation is new and exciting for both of you. The more contact you have, the more you will get to know and understand each other. On the ward you have an experienced team to assist you dur-
ing the first phase of getting to know each other and give you instructions and support.

Kangarooing – closeness for parents and child

The so-called kangaroo mother care is, once the initial feeling of insecurity has gone, for most parents a precious and intensive experience of closeness and intimacy with their child. Lasting calmness, deep sleep, an often more regular heartbeat and better oxygen values are an indication for a successful contact. For your child regular kangarooing represents a decisive support for his further physical and mental development. You can ask the nursing staff as well as physiotherapists to give you instructions on how to perform kangaroo care with your child.

Learning to understand your child’s signals

The more time you will have spent with your child, the better you will be able to understand his signals and adjust to him. Your baby initially communicates with you mainly by his behaviour, but his signals are especially in the beginning still very unclear. The longer you watch him, the better you will know how he feels and what he needs at what moment. You will find out his favourite lying and sleeping position, notice how he likes to be held and how to be fed. You will know how he behaves when he is awake and alert and ready to interact with you. And you will learn what excites and overstrains your child, how to calm him down and when he needs a rest. You will also know when he doesn’t feel well and how to help him then. This growing experience will manifest in a secure feeling as mother/father of your child.

Don’t forget to look also after yourself and to attend to your own needs

Certainly you will sometimes not be able to stay with your child as long as you want. Especially in wards without restricted visiting hours parents often have the feeling that they must stay 24 h with their child if they want to be good parents for him. However, it is important that you attend also to your own needs for rest and recovery. Timeouts at home or even days where you don’t come to the clinic are necessary in the course of many weeks and months to prevent you from being completely exhausted when your child is discharged to home. This first phase after the too early birth is not only stressful for your child, but also for you.

As the relationship and bonding between parents and child is gradually developing, you don’t have to be afraid that the initial separation has a
long-term negative impact on your relationship. It is less important how long you stay with your child, but how you spend this time. Experience has shown that time spent together regularly but shorter in terms of hours, which is experienced relaxedly, is for both parents and child the most beneficial.

Talk about your fears and concerns

Most parents feel it is inappropriate to verbalize their own mental state and particularly try to be there for their child and to function in daily life. They often doubt their importance as parents of the baby, have a feeling of strangeness towards the child. Many of them ask themselves, if they might have contributed to the premature birth of the child and are concerned about the health and future development of their baby. Such feelings and thoughts trouble many parents and you should not hesitate to accept the offer to talk about it. Those services can vary from clinic to clinic. The staff of the intensive care unit can tell you the right person to talk to. Besides professionals trained in parent counselling, many clinics have organized parents’ self-support groups that will gladly offer you advice and assistance. It is important that in these discussions you pay attention to whether you are able to benefit from the experiences of other preemie parents at the moment or whether it is a rather stressful expe-
rience for you. In the latter case, it is perhaps too early for such an exchange of experiences. Should concerns, fears and mood swings persist and talking about it is not relieving, you should seek professional psychological or medical-psychotherapeutical assistance. This possibility systematically exists only in a few clinics, but should be orginazable by the ward on a consular basis.

Accept help in daily life

Only a few people in your environment will be able to understand what are just going through. Therefore they will find it difficult to offer you sensible help on their own initiative. You should not hesitate to ask friends and relatives for practical help regarding everyday tasks, the household or the care of siblings. Every relief in these areas means a little more time for your new family member.

The development of a safe bond between you and your child does, of course, not depend exclusively on the relationship development during the first weeks or months of intensive medical care treatment. You should, however, consider that any kind of positive contact during this time will be the basis of your future social interaction. And a safe bond is a decisive factor of protection over the whole course of life. With this in mind we wish you a lot of strength, patience and confidence in the coming weeks and months and delight in your child!

Contact

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Help for the siblings

Dr. Frank Pastorek, Association “Hilfe für krebskranke Kinder”

Changes are an integral part of human life. This is an experience children already go through at an early age and it influences on their feelings, sensations and thoughts. Children perceive difficult situations in life even more intensively. From this angle has to be seen the situation of families which are forced to adjust too early to their new arrival and to deal with the unforeseen problems of a child born too early.

After a premature birth the whole attention is focussed on the new family member who has arrived too early. The necessity not to lose sight of the healthy siblings specifically during this time arises from the special situation of these children.

Even under “normal” circumstances the enlargement of the family by another sibling already implies a certain “rivalry”. When parents now, for understandable reasons, focus their attention and special affection on the premature baby, the siblings may feel pushed to the margin of the family. The newborn is then presumed to have caused the changes in the family and is held “responsible” for the fact that the sibling apparently has lost a large part of his parents’ love and affection.

The age of the siblings is decisive for how they experience and cope with the situation. Until approximately six years of age, the child is mainly influenced by the sorrows and concerns of his parents. It is therefore important that you involve the siblings and try to explain the situation to them. The parents’ confidence in the further development of the baby born too early will have a calming and reassuring effect on the sibling.

The following years until the onset of puberty are characterized by more understanding, and own considerations fire the children’s imagination. Also during these years, cautious attempts to explain can avoid or alleviate fear. The parents’ special attention given to the prematurely born sibling must not be felt like the “withdrawal of affection”. It is helpful to involve the children in the exchange of information within the family and to regularly offer them dialogue through mom or dad. Rituals help and provide a stable framework that sustains and supports. If possible, set a fixed time in your
daily routine where questions can be asked and answers can be given. If siblings are temporarily entrusted to the care of their grandparents, friends or persons close to the family, special attention should be given to keeping habits and regular (phone) contact with the parents in order to counteract the feeling of loneliness. Behavioural problems or performance deficits in school can at this age be an indication of emotional difficulties. In this case, too, affection and integration into what is happening can help.

If the siblings can be integrated into the temporarily changed rhythm of the family, the whole family will draw strength from this situation and emerge stronger from this time.
Assistance through mother’s voice and music

Dr. sc.mus. Monika Nöcker-Ribaupierre, Munich

In the intensive care unit your child has been placed into a totally different loud, unpredictable world, determined by technical noises. Everything he has heard before does not exist anymore; he mainly hears foreign voices, his mother’s voice is completely missing. He can’t do anything against this often chaotic noise. On top of that, the incubator reinforces the noises from outside (there is a sound level of 50-109 dB inside the incubator). Coping with this consumes a lot of the baby’s energy, which he rather needs for his growth and development.

Comprehensive research has shown that music and of the mother’s voice can be used to help and encourage the infant’s development. In this connection, individually designed programs should be used. A ward-wide constant stream of background music overstrains your child and is therefore to be rejected.

If you as parents want music played to your child, it would be fine and helpful if you participated in choosing it. For many intensive care units that’s new territory even today and maybe associated with trouble and assertiveness for you. And often, at least in the beginning, it may seem inconceivable that such a tiny baby may benefit from hearing music or his mother’s voice from a tape. It also requires listening attentively and getting a feeling for your baby, which you can often not even identify between all the technological equipment. One thing is certain: the baby can hear. His ability to hear has been developed even before the earliest date of premature birth; when the baby is born, he has already got a hearing experience of many weeks. If you talk to a baby in the incubator watching him closely, you can see that he hears you.

You can arrange yourself the music for your baby – there is also some particularly composed or arranged music: lullabies and cradle songs with violin or guitar accompaniment, relaxation music with or without nature voices. But maybe you have also music the baby already is familiar with from his time in your womb? When choosing the music you can also think about which children’s songs, lullabies or cradle songs you would sing to your child if he were at home. In any case, you as parents (or also the nurse) should listen very closely and watch the child when you play music to him. Because every child,
however small it may be, has an unmistakable personality and has his own preferences.

As a mother of an extremely immature preterm baby I have been working for years as music therapist on a neonatal intensive care unit. I experienced that mothers often had reservations about playing music (e.g. from Mozart) to their child in the incubator – in contrast to their readiness and pleasure about recording their voice for their child. The music-therapeutical method which has been developed from this (auditive stimulation) is helpful for both mother and child. Because: the voice of the own mother, which means your voice, is – in contrast to the “canned” music something unique, unmistakable and familiar – something your baby already knows from his time in your womb. Research has shown that there is a double effect: on the one hand it helps the baby to cope with the stress on the intensive care unit, on the other hand it helps you as mother to overcome the emotional crisis which may exist after the birth – just because you can do something for your baby and leave something for him only you can do, no one else. Your voice means to both of you a bond which persists from the life inside the womb over the time in intensive care to the home – it helps both of you to re-establish the bond which was abruptly interrupted due to the too early birth.

When recording your voice, you should look for professional help in the clinic or – if this is not possible – do it at home and pay attention to a good sound quality. You can read a story or a prepared letter to your child, tell him about the home or sing – just as you like.

Please keep the following in mind:

- Use small, but good-quality speakers for transmission. Don’t use headphones which transmit the language or music directly into the ears of your baby. This is easily underestimated; tuning of the volume is difficult, therefore it can be harmful.
- The voice respectively the music should not be played more than 5 times a day for 30 minutes.
- The volume should be adjusted in such a way that it can be heard above the basic sound of the incubator.
- Day and night-times must imperatively be observed.

When medical or nursing measures are carried out, please, don’t play the voice/music in order to prevent the baby from learning to associate disturbance/pain with the mother’s voice/music.
It is good, however, to play the music/the voice, when the baby is calm and prepared for it, e.g. after the meals or when you are leaving the child, so that something of you stays with him. The recording cannot replace the human contact and should therefore be stopped when you are with your child.

If you absolutely want your child to hear a musical clock, maybe because this was your favourite music when you were a child or because it has been brought by an older sibling, you should carefully check the musical clock for good sound and put it then wrapped into a diaper etc. at the foot of the incubator, far from the baby’s ears.

Finally, it is expressly pointed out that we are talking here about music/voice which has been prepared for the individual child and is only played to this child in the incubator. It is not a question of subjecting the entire intensive care room to music sound. This would be far too loud for the children and does not take into account the baby’s individuality. Music in this form can certainly improve the mood of nursing staff and parents facilitating thus the work and the stay in an intensive care unit, but for the children it represents an additional noise disturbance. Especially in such an extreme situation, special attention has to be paid to what does the individual baby good, and therefore the music can only be used purposefully.

Should your child need further therapy, the music therapy is a good possibility.
Everything you as parents want to do for your child has to be discussed with the ward staff. The doctors are responsible for what happens on the ward. The nurses and caregivers are the persons who take most care of your child and often have established a special relationship with him. Therefore it is important and necessary to discuss with them, to ask them for advice – or even clearly talk with them about your own needs concerning your child.

**Literature for parents**

“Förderung frühgeborener Kinder mit Stimme und Musik”
by M. Nöcker-Ribaupierre und M. L. Zimmer, Reinhard-Verlag, 2004

**Contact**

Dr. sc. mus. Monika Nöcker-Ribaupierre
Wehrlestraße 22
D-81679 Munich
email: mnoeckrib@aol.com
Does your newborn child hear?

Dr. Daria Schreyka,

The ability to hear from the very beginning plays a decisive role for your baby’s overall development and his future. If your baby can’t hear well, this will affect his language development, his behaviour, his psychic balance and later his career in school.

A hearing impairment is the most frequent congenital sensory disorder. By simple screening, however, it is possible to exclude a serious hearing impairment in the first days of life already. There are two different methods of screening to test your baby’s hearing. They are simple, quick and painless and can take place while the baby is sleeping.

One hearing screening, the so-called newborn hearing screening must be performed especially on premature babies. This screening should be carried out after the birth in the maternity clinic already or during the first days of life at the U2 (= well baby check up days 3-10) or U3 (well baby check up weeks 4-6). It can be more difficult to carry out the hearing screening in a premature infant. Preemies are more restless, they move more and their auditory canal is smaller. Therefore
the specialist possibly will need more time to obtain a result. However, the screening can be carried out well and reliable even in premature babies. It becomes more and more common to examine premature babies on the neonatal care unit already for a hearing disorder. It may be necessary to repeat the newborn hearing screening after discharge from the clinic until an unambiguous result is obtained.

A conspicuous hearing screening will lead to an immediate extensive diagnostic workup of the ability to hear. If the finding of a hearing disorder is confirmed, a therapeutic treatment as well as appropriate early intervention methods will be immediately initiated. By the early recognition, rapid treatment and intervention every premature baby with hearing disorder can learn to hear and to talk within the scope of his abilities. Therefore, ask your midwife, on the neonatal ward, your pediatrician, the social-pedagogical centre or an ENT doctor or phoniatrician/pediatric audiologist for a hearing screening (neonatal hearing screening).

Pay attention to a good hearing of your baby – from the very beginning!

Information: www.fruehkindliches-hoeren.de
Follow-up document

Christiane Stock, project group NSP Hamburg

Description

For more than ten years, members of the Association Frühstart Hamburg e.V. have been caring about parents of premature children. In this connection the follow-up document was developed by concerned parents in collaboration with doctors and therapists. The second edition is now available since June 2007.

The follow-up document is a solid folder containing all information and documents. Unlike in the yellow infant health check-up booklet in which health disorders are described by code digits and no therapies such as physiotherapy are mentioned, in the follow-up document are listed in detail the key data of the first weeks of life and is documented the further development of the child.

Content

The follow-up document is subdivided into six sections:

- Medical facts, for instance discharge data,
- Follow-up examinations up to 2 years, specialists’ examinations, drugs
- Statements on therapies such as physiotherapy, ergotherapy etc.
- Personal data such as siblings, childminder, long-term care insurance
- Foreign terms glossary
- Various sealable plastic covers for infant health check-up booklet, vaccination record, X-ray registration card etc.
- Section for additional own reports

We have available the following additional pages which can be attached if need be: cardiology, epilepsy, home monitoring, gastro-enterology, and neurosurgery.
Advantages for families

This follow-up document is intended for parents of premature children to keep all information and documents (doctor’s reports, vaccination records/X-ray registration cards) in a folder so that conversations with the doctor can be shorter, parents don’t have to talk about serious diagnosis in the presence of their child and more time is left for the examination of the child. The follow-up document is particularly helpful for parents of twins respectively multiples to avoid confusion of the childrens’ findings. In case of sudden emergencies the hospital doctors can see the patient history at a glance; parents are often nervous in such a situation and therefore not able to extensively report on the situation.

In addition, the follow-up document is also helpful for families who are moving and are looking for the appropriate doctors and therapists for their child at their new place of residence.

Advantages for doctors and therapists

Everyone only enters his own findings/examination results, has only to make few notes, so that the maintenance of the follow-up document, which is really important for concerned families, does not require spending much extra time.

The follow-up document gives doctors, therapists, nursery teachers etc. within short time a comprehensive overview on

- anamnesis
- status quo
- diagnosis
- forms of treatment
- previously administered drugs
- achievement of developmental milestones, e.g.
  - when did the child start crawling
  - when did he start talking
- Care level and degree of disability of the child
The follow-up document networks all those who are involved with the child in most different forms; it contributes to avoid double treatment. It is very useful in a possible readmittance to hospital.

Use/application in practice:

- Parents can get the follow-up document from the discharging clinic. If follow-up documents are not yet available in the clinic, they can be ordered from the project group ‘Nachsorgepass’ c/o Frühstart Hamburg e.V. (info@nachsorgepass.de). The follow-up documents are free of charge; only packaging and shipping expenses are invoiced. This allows also parents to order individual copies if needed.

- Clinics should discharge premature babies and ill newborns, where it is sensible and necessary, with a follow-up document in which the pages perinatal data and discharge data have already been filled in (in addition to the baby health check-up booklet).

- Parents also put detailed doctor’s reports into the folder and keep the baby health check-up booklet, the vaccination record, X-ray pictures etc. in the plastic cover and bring the follow-up document to every examination in order to have new examination results entered into it in short form.
Vaccination of premature infants

Dr. med. Franziska Schaff and Prof. Dr. med. Heinz-J. Schmitt, Mainz Johannes Gutenberg University

Should premature babies be vaccinated? This is a question many parents worry about. Because on the one hand premature babies are likely to be more susceptible to infectious diseases and everyone wishes for an optimal immunization protection especially for those children. But do the available vaccines actually offer effective protection for premature babies? Do increased side effects and complications occur in this particularly “delicate” patient group? The uncertainty is often due to a lack of substantiated information so that the recommended immunizations are often delayed or not given at all. In the following we have compiled some important information and concepts regarding the vaccination of premature infants.

Risk of infection
Newborns are at particular risk of some infectious diseases and this risk often is even higher in premature babies. Whooping cough (pertussis) especially threatens unvaccinated infants under the age of 6 months. Premature infants are also more vulnerable to hepatitis B. They still have an immature skin and mucosal barrier and receive more often blood and plasma products. The younger the children are, the more often the course of disease is chronic. Chronic (lifelong!) infections again systematically lead to cirrhosis of the liver or to liver cell cancer. Due to the immature body defense (the immune system) infants – and here again particularly premature infants – are vulnerable to serious infections with encapsulated bacteria (meningococcus, pneumococcus, Haemophilus influenzae type B). These pathogens come from the nose-throat area and pass into the blood and give then rise to severe “blood poisoning” (sepsis) or they may reach through the bloodstream inner organs and subsequently cause meningitis, synovitis or other organ inflammations.

Premature babies and newborns are at significantly higher risk of coming down with a serious flu (influenza). Within the frame of the annual epidemics they have to be treated the most frequently in hospital.

Rotaviruses are the most common cause of diarrhea in young children; and here again the disease runs a more serious course in premature babies. An infection acquired in hospital may considerably lengthen the stay in hospital, however, death or permanent damages are very rare.
As premature babies receive less maternal antibodies from the mother due to the shorter pregnancy, they are less protected e.g. against measles than full-term babies. Especially nurslings are at high risk of becoming seriously ill with measles with long-term damages. RS viruses (RSV) infect nearly every child at least once by the age of two years. Whereas the disease in older children and adults normally takes the course of a slight cold, particularly newborns may become seriously ill with bronchiolitis or pneumonia and have to be treated in hospital. In very small premature infants and those with a lung disease or a serious congenital heart defects, but also in children with underlying neurological disease, the disease takes an even more serious course – these patients require more often an intensive care treatment or mechanical ventilation.
What happens after vaccination?  
Particularities of the immune system in premature infants

In general, there are killed and live vaccines. Killed vaccines (e.g. sixfold immunization, vaccines against pneumococcus, meningococcus, influenza) contain e.g. protein or sugar components of the germ against which the body produces protective repellents, the so-called antibodies. Killed vaccines cannot themselves trigger a disease. Fever, restlessness or pains and swelling at the vaccination spot are signs that the human immune system is “dealing” with the vaccine.

Live vaccines contain germs which have been weakened to the point where they cause a slight infection without risk for the vaccinee. Therefore, vaccine reactions, e.g. fever and skin eruption after a measles vaccination may occur after a life vaccination.

Parts of the immune system are closely working together in the child’s body. Distinction is made e.g. between B and T lymphocytes, antigen-presenting cells, cell messengers etc. The results of this collaboration are first the production of protective specific antibodies and specific defence cells and second “memory cells”. Memory cells can remember the relevant infection even years after the vaccination and quickly react to it by producing antibodies or with other defence mechanisms.

Premature infants also have all the necessary components of the immune system. However, networking, communication and function are still immature. Therefore premature infants can also be vaccinated – the protective effect may, however, be a little lower than in full-term infants.

The above mentioned vaccines provoke an active immunization, which means that the immune system of the child deals with the vaccine and “actively” produces itself e.g. protective antibodies. However, against some diseases no effective vaccines have yet been developed. In these cases it is possible to introduce protective antibodies directly into the blood in order to repel infection. This procedure is called passive immunization.

Vaccination success – are premature infants sufficiently protected?

Since many parts of the immune systems are involved in a vaccination, it cannot be measured by a simple laboratory test whether and how successful a vaccination was. Although it is easy today to measure antibodies against the vaccine in the blood, it is not yet possible to routinely detect the defence cells which are likewise essential
for a protective immune response. Antibody concentrations ("titres") are today, however, in studies the most important components to prove the success of vaccination, because they can be most easily measured. That’s also plausible, because if antibodies are detected which couldn’t be proven or hardly proven before, one can be sure that the child’s defence system has reacted to the vaccination! Therefore antibodies are indeed a criterion for the immunization protection. However, since there are besides antibodies also other protective mechanisms of the defence system, one may in particular cases also be protected against a disease if no antibodies have been detected after vaccination. Timely vaccinated premature infants, that mean premature infants vaccinated according to the chronological age, produce in most cases specific antibodies against the vaccine. The amount and the concentration of the produced antibodies are, however, slightly less than in full-term infants; there are also some indications that the antibodies fall a little sooner below detection level – the memory cells remain, however, detectable. Therefore, according to modern knowledge premature infants are also protected by vaccination – it remains, however, unknown whether this protection is as effective as in full-term infants. Therefore it is imperative that parents ensure the recommended booster vaccinations be given at the age of 2.

Side effects of vaccinations – Particularities in premature infants

The Permanent Vaccination Commission of the Robert-Koch-Institute (STIKO) has compiled information on the side effects of each vaccine available in Germany. Vaccinations have typical undesired local and systemic side effects such as e.g. reddening, swelling and pain at the injection site as well as fever. Those can be observed with killed vaccines during the first 48 (-72) hours and do not occur more often or more seriously in premature infants compared to full-term infants. Besides, respiratory pauses (apneas) and "slow heartbeat" (bradycardias) may increase or reoccur in premature infants during the first 48-72 hours after vaccination. The oxygen need may also temporarily increase in infants needing oxygen. These side effects particularly occur in very small premature infants (<1.500 g) and here especially in those who, at the age of 8 weeks, are still suffering from apneas and/or bradycardias or who are still dependent on oxygen. This is, however, a temporary phenomenon; long-term or serious side effects, a prolonged hospitalization or serious feeding difficulties have not been described.
Complementary measures

Besides the immunization of the premature baby there are sensible complementary measures to reduce the risk of infection. The persons in the baby’s environment, which means the staff on the intensive care unit respectively in the hospital and persons at home who have close contact with him (parents, siblings, relatives, all contact persons from the nanny to the friends) should get immunized against pertussis and in autumn also against influenza to prevent an infection of the premature infant. Contact to persons and family members with a potentially transferable disease should be avoided. Women who want to get pregnant should complete respectively booster immunization already before pregnancy (pertussis, measles, mumps, rubella, varicella, maybe pneumococcus, meningococcus, Hib). In individual cases vaccination of pregnant women may also be sensible (tetanus, influenza or other).

Summary and conclusion

Premature infants have compared to full-term infants a significantly higher risk of getting infections avoidable through vaccination, often even with particularly serious courses. Studies on timely vaccination of premature infants show that the large majority of the premature babies produce protective antibodies, even though the amount is
slightly less than in full-term children and the antibodies decrease sooner. According to present knowledge, early immunizations provide, however, a good protection whereby the immunization itself does not represent a higher risk. Typical side effects do not occur more frequently in premature infants than in other newborns, however, there may be a temporary increase or a reoccurrence of apneas and/or bradycardias. No long-term serious side effects are known.

We therefore advise – like most scientists, pediatricians, respective associations and expert commissions worldwide – to timely administer to premature infants the vaccinations recommended by the STIKO for all children, which means according to the chronological age. In this connection, combination vaccines are supposed to be used. In very small premature infants who are still in hospital at the time of vaccination, a monitoring should be carried out for 72 hours. Premature babies should also receive the life vaccinations and the booster vaccinations at the end of the first year of life in order to build up a long-term effective immune protection. Children with a particularly high risk for RSV infection should receive during the whole RSV season once a month antibodies against RS viruses. The pediatrician decides whether your child is particularly at risk on the basis of your child’s anamnesis and the recommendations of the respective associations.
Further literature and information
Comments on the prophylaxis of serious RSV infections in children at risk with Palivizumab.
Homepage of the DGPI (German Society of Pediatric Infectious Diseases) 2006.
www.gesundes-kind.de
General information about vaccination;
possibility of asking questions
www.impfbrief.de
Current information for doctors on vaccination

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How to prevent cot death in premature infants?

Christian F. Poets, Tübingen University Clinic

Former very small premature babies (born before the 37th week of gestation, birth weight < 2500g) are at an increased risk of cot death (Sudden Infant Death Syndrome, SIDS). Therefore many parents wonder how they can protect their child from it after discharge from the clinic. In the past, these children were often monitored during the whole first year of life. This has become rare today, because such a monitoring can be very stressful for both parents and the child due to many false alarms and it has not been proven to protect from cot death. Unlike before, we know today very well which measures are suitable to reduce the risk of cot death by approx. 90%. Parents should be informed about these measures which particularly concern the positioning of the child, in order to contribute themselves to prevent sudden infant death.

Parents intuitively know how to recognize their child’s needs.
Sleeping position and risk of cot death

For full-term infants (which means babies born at 37 weeks of gestation or later) the tummy sleeping position is associated with an approx. 6 to 8fold increased risk of cot death. For premature infants (babies born before the 37th week of gestation) this risk is even potentiated, namely by 39-fold respectively in a Scandinavian study even by 83-fold (in each case compared to full-term children, sleeping on their back). Premature babies sleeping on the side have a 40-fold increased risk. It is therefore imperative that tummy and side position are not used particularly for those children: they should be put to sleep on their backs!

The increased risk of cot death in tummy position is explained by the fact that in this sleeping position the baby is more likely to “sink down” with his face into the bedding, which means that the nose is covered; due to a defective arousal reaction which normally allows children to get out of this dangerous situation by turning the head, they suffocate. This would also explain why soft bedding such as e.g. sheepskins considerably increases the risk of cot death.

As long as small premature babies or sick newborns are still in the clinic due to their unstable breathing, they are, however, put to sleep in the tummy position. This is done, because several studies showed at the beginning of the seventies already that premature babies and newborns in tummy position have significantly less and shorter breath holds during sleep and show a larger lung volume, higher oxygen values, less drops in oxygen saturation and heart rate as well as longer sleep periods with more deep sleep. Since there has been reported no cot death so far on neonatal intensive care units (perhaps due to the permanent monitoring as well as the very young age) nothing can be objected here to putting the baby to sleep in the tummy position.
However, as soon as the breathing situation of these children is getting better, we put them to sleep on their backs in our clinic; in premature children who have already been staying a long time in the clinic, at least one week before the planned discharge; At the same time, we explain to the parents that their baby is better now and that it is therefore put to sleep now like he is supposed to sleep at home after discharge: in a sleeping back and on his back.

This procedure has two advantages: on the one hand a possibly occurring transitory sleep disturbance resulting from the change of the habitual sleeping position can still be absorbed in the clinic and is not an additional burden for the parents; on the other hand, the clinic sets an example. Like in many areas of daily life, parents tend to adopt something which has been exemplified to them rather than what has only been recommended to them.

In our opinion, prescribing monitoring to prevent cot death doesn’t make sense for premature children. We only prescribe a pulse oximeter for home monitoring if a premature infant still shows bradycardias and drops in oxygen, but can apart from that be discharged. Just like in the clinic where the monitoring would not be discontinued as long as these symptoms still occur, we offer parents in these cases the possibility to take their baby home and continue monitoring for a few weeks, which means until the probable disappearance of these symptoms. The aim of the monitoring is thus not to prevent cot death, but to prevent episodes of oxygen deficiency. A precondition for a discharge with the monitor is, however, that we have shown the parents before how to react in case of a monitor alarm (including resuscitation training on a puppet) and that they have confidence (and we have confidence in them) in their ability to manage such a situation.

Besides the right position, there are further important measures which may reduce the risk of cot death. These include the following recommendations of the Society for pediatric and youth medicine:

- Let your baby sleep in your room, but in his own cot.
- Don’t let your baby’s head slip under the bedding; avoid pillows; the best is to use a sleeping bag.
- Don’t let your baby get too hot: 18 °C room temperature and a sleeping bag are enough.
- Don’t let anyone smoke in the same room as your baby.
Breastfeed for as long as possible.

If your baby has a dummy, be sure to use it every night.

Finally, the overall aim of these recommendations is to create a sleep surroundings where the risk is as reduced as possible that your baby suffocates while sleeping respectively may not awaken early enough from a threatening situation.

Besides, we also recommend making use of the generally recommended vaccinations for babies, because several studies have shown that children who had been vaccinated were less likely to die from sudden infant death than those unvaccinated.

As stated above, the frequency of cot death has decreased by approx. 9% in countries respectively regions that have consequently implemented the indicated measures, such as e.g. the Netherlands or Styria. This should also in Germany be the right incentive to consequently adopt these measures particularly for our sensible “tiniest ones”.

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Information material

Brochures for parents

Premature babies during the first weeks of life

by Dr. Klaus Sarimski, Munich and Dr. Friedrich Porz, Augsburg

This brochure is intended to assist concerned parents and interested specialists trying to get an idea of the developmental conditions of premature babies and of the possible aids.

Preterm babies after discharge

by Dr. Klaus Sarimski, Munich and Dr. Friedrich Porz, Augsburg

Many parents report that they did not feel well prepared for the first time after discharge from hospital. This brochure is intended to show the concerned parents the most frequent particularities of premature babies.

Preterm infants and their parents in the clinic

by Dr. Monika Nöcker-Ribaupierre, Munich

This brochure is intended to give a practice-oriented overview and is meant to be of specific assistance in the ward situation.
Nutrition of premature infants

*by Prof. Dr. Christoph Fusch, Greifswald*

This guide deals with the nutrition of premature infants until solids are introduced. Parents are shown what has to be observed and what will help them to optimally feed their preemie.

All publications can be ordered from the Federal Association or in the preemie shop at [www.fruehgeborene.de](http://www.fruehgeborene.de)
The Bundesverband – a word from the editor

The Bundesverband “Das frühgeborene Kind” e.V. was founded 1992 in Frankfurt am Main to

- inform and support concerned parents and relatives of premature infants,
- provide support to regional self-help groups and parents’ initiatives for premature infants,
- push forward the education of the general public on the situation of premature infants and their families in trade journals, radio and television,
- create a lobby for premature infants on a socio-political and social basis.

In November 2003 the Federal Association opened its drop-in and information centre in Frankfurt/Main, the Premature Infant Information Centre (FIZ). This is a contact point where concerned families, parents’ initiatives, early intervention services, media and all interested persons can address their inquiries to the Federal Association. To implement further objectives, we need your support! Please, help us with your donation or sponsor membership to implement the tasks of the Federal Association on behalf of the tiniest ones of our society! Thank you very much!

*Donations account see at the back of the brochure*
To the Bundesverband
“Das frühgeborene Kind” e.V.
Speyerer Straße 5-7
D- 60327 Frankfurt am Main

Application for membership

Yes, I/we want to become a member of the Bundesverband “Das frühgeborene Kind” e.V. as

☐ sponsoring member (family/single person, 50,– Euros per year)
☐ full member (parents’ initiatives, 60,– Euros per year)

Parents’ initiatives

Name/Contact person

Address

Phone/Fax

email

Place, date, signature

Collection authorization

The membership fee in the amount of .......... Euros per year will be collected from the following account:

Account no.  sort code

Place, date, signature
Subscription

Yes, I would like to subscribe to the newsletter “Das frühgeborene Kind” (The premature infant)

☐ starting with the first issue of the current year

☐ starting with the issue for the .......... quarter of year .................

☐ if already published, I would like to order copies on the main topic

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Notice
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“Das frühgeborene Kind” e.V.

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