

Bonding with and caring for preterm born babies

A guide for parents and families





Dear Parents,

Congratulations on the birth of your baby! Although it is true that your baby girl or boy was born too early, you can rest assured that you can rely on the experience of the doctors and nurses in your hospital.

Globally, about 10% of all births are preterm. This is why research into the care and treatment of preterm babies is quite advanced. Yet parents often feel overwhelmed in the face of high-tech medicine.

Research on bonding has shown that both in the neonatal intensive care unit and later at home certain factors are very important for your child's optimal development. These include, for example, your presence as parents as well as following the principles of developmental care. You can build a good and lasting bond by being present, using your voice, and caressing your baby. These methods have also been proven to be highly effective in stabilising a baby's heart rate and oxygen saturation. Even if your baby is born too early and you have to let healthcare specialists take care of them in the beginning, you remain the most important people for your baby. You are the parents, after all!

We hope that this brochure will give you support and advice on how to initiate and shape the bonding process and how to give the best care to your preterm baby. We would also like to warmly thank the company Nestlé for supporting this brochure.

Yours sincerely,

A handwritten signature in black ink that reads "Silke Mader". The signature is written in a cursive, flowing style.

Silke Mader

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The importance of attachment for preterm babies and their parents

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The number of preterm births is increasing, so, like you, more and more parents have to face the early birth of their child. The first weeks or months after having a preterm baby can be very stressful, especially if they are born before the 24th week of gestation. Moreover, caring for a preterm child can remain a challenging task for many years.

Once your baby is born, they will most probably be separated from you and receive medical treatment in the hospital. Your baby will be put in a life-saving incubator. There, the infant will be exposed to medical equipment and will depend on fixed schedules and procedures within the neonatal ward. In addition to worrying about the survival of your child, which is a constant wavering between hope and fear, you also have to hand over your parental responsibility to physicians, nurses, and even technical equipment. In this new and unexpected situation, immersed in a high-tech environment, it is more than understandable that at first many parents feel overwhelmed by the situation. There are phases of guilt, fear of failure, and self-doubt. Some parents even suffer from exhaustion and/or periods of depression.

Your pregnancy was shorter than expected, meaning that you were pushed abruptly and surprisingly into the role of being a parent. Much of the attachment process, which normally develops gradually between parents and baby during pregnancy and birth, is suddenly cut short by the preterm birth.

Even if there are generous visiting hours at your hospital and you can be with your baby up to 24 hours a day, it is not so easy to build a relationship with and touch your baby if they are in the incubator or too fragile to carry in your arms.

Basic needs of newborns – special needs of preterm babies

Every small child needs affection, stimulation, care, and protection. To feel comfortable and to develop healthily, the child needs to build stable relationships and experience self-sufficiency to eventually build their own personality. The feeling of belonging to a family or to a group of loved ones provides direction and support to every child – and of course also to babies born preterm.

Right after birth, babies continue to grow and develop by continuously communicating and engaging with their environment. Therefore, babies need the support of familiar, reliable, and available adults – ideally you, their own parents. They also need to be in regular contact with other children whom they know well and are already close to.

Caring for a baby born preterm can often take a long period of time and is a joint effort by the professional team of your hospital, in particular the intensive care nurses, and the parents themselves. However, depending on your baby's health status, you as the parents should be involved from early on in the care and nurturing of your baby. The paediatric nurses should support and encourage you to take on the role as caregiver.

For you to become your baby's close, reliable, available, and sensitive attachment figure, you need a lot of time and a good support network. This is especially important not only while your baby is in the clinic or in the intensive care unit, but also after discharge from the hospital.

There are some basic needs that should be met to help your baby develop in a healthy manner:

Basic physiological needs

Air to breathe, enough to eat and drink as well as sufficient sleep and warmth are some of your baby's most vital needs that must be met. To survive, your baby also depends on nurturing care. Therefore, it is crucial for you to recognise your baby's needs, to interpret them "correctly", and to act immediately and appropriately on them.

The need to be safe and to be protected

Without affectionate and reliable care, your baby would be just as lost as without water to drink or air to breathe. Without attentive care, they would neither grow nor develop in a healthy manner. From birth on, your baby has the need to bond with a person that can provide protection and safety. You can observe this need, for example, when you see your baby reacting to your voice or your loving touch.

This behaviour, ultimately aimed at ensuring their own survival, is called attachment behaviour. Small babies and children who have a secure attachment with their parents start calling, crying, and protesting when left alone. For them, their parent represents a "safe haven" that reliably provides protection which they can always resort to when they are afraid or if there is some kind of "danger". Babies might have this feeling of "danger", for example, because of sensory overload, uncertainty, or separation from the parents. It can also be caused by disease, pain, tiredness, nightmares, or other reasons.

Your baby born preterm is much more vulnerable to many of these stress factors; therefore, your baby's need for attachment is even stronger than it is for babies born full-term. At the same time, due to the circumstances, it is more difficult for you to meet this need since touching, holding, and protecting a baby born preterm is more complex. However, day by day, you will learn how to better observe and understand the sometimes-subtle signals, and how to react adequately by using physical contact, your voice, and affectionate attention. It is not something you will manage to do perfectly overnight, so it is best to learn step by step and with the help of an experienced paediatric nurse. Slowly but surely, you will learn to understand what the signals of your baby mean and how to react to them best.

Safe bonding is the basis for personality building

The attachment process between you and your baby already begins before birth. It is significantly shaped by your experiences during pregnancy, birth, and the first months of life. A strong and stable relationship between you and your baby constitutes an important basis for how your child, as an adult, will behave towards other people and in the face of problems or difficulties. The quality of the attachment between you and your child determines how your child will behave when dealing with other people or challenges. If you raise your baby in a supportive and sensitive way, they will very likely perceive themselves as lovable and competent later in life.

Studies regularly show that older children who are securely attached to their parents are, for example, able to better control their feelings of aggression and frustration. They also have higher self-esteem and self-confidence, better interpersonal skills, and an improved ability to cope with difficult situations. What is more, they are more creative and have advantages in speech development. Emotionally neglected children, by contrast, develop a negative self-image. They often do not view themselves as lovable or accepted and respected people, which makes building trusting relationships later in life more challenging.

Attachment for survival

Secure attachment with a person who provides protection, care, and support, is an innate and fundamental need for a baby. It ensures the baby's survival and healthy development.

The need for bonding when frightened or lonely

It is especially important for you as the parents to be involved in the care of your preterm born baby as much, as early, and as comprehensively as possible to strengthen the relationship with your baby and to ensure their survival and healthy development. In this context, we would like to mention a phenomenon called “hospitalism” which was already described in the 1930s and 1940s by psychoanalyst René Spitz. Spitz observed babies and infants who were raised without a sensitive and affectionate attachment figure, e.g. infants in a children’s home. He found that those children were often shorter in height and had a smaller head circumference because of reduced brain development. Today we know that these symptoms are caused by a lack of the human growth hormone, which is not sufficiently produced when babies are emotionally neglected. Even if the babies are fed with plenty of calories, they will not grow and develop accordingly. Having made similar observations, clinics are increasing their efforts to feed preterm born babies as early as possible with breast milk instead of artificial infant formula, as babies can digest breast milk more easily, absorb the nutrients better, and generally show a more positive development. At the beginning, when preterm born babies are too weak to suckle at their mother’s breast, they receive pumped breast milk via baby bottle or feeding tube. Once the baby is stronger, it is advisable to switch to normal breastfeeding. If there are no medical reasons against it, parents should take the opportunity to not only feed the baby but also to bond and strengthen the relationship.

For your preterm born baby, growth is even more fundamental for survival, so any kind of emotional care by you, the parents, or by the nurses will improve your baby’s development. Kangaroo care, a method of holding your baby skin-to-skin on your stomach, is very beneficial. It is important that both you and the baby feel comfortable doing this. The skin-to-skin contact will initiate the release of the hormone oxytocin in both the baby’s and your body. Oxytocin has many positive effects: you and your baby will be more relaxed, you will feel emotionally closer to each other, and the attachment between you will intensify. Oxytocin also increases milk ejection from the mammary glands, which has a positive effect on breastfeeding and milk production overall.

Kangaroo care not only strengthens the relationship with your baby in the first weeks; it also makes preterm born babies gain weight faster. Research has shown that intensive kangaroo care (which includes frequent and extensive kangarooing and breast feeding, if possible) has a particularly positive impact on the general development of the preterm born baby into adulthood. By the age of 20, the preterm born babies who received kangaroo care by their parents showed a better development of the brain, less aggressive behaviour, and less hyperactivity. Their social and learning skills were also better developed.

It is important to mention that caring for the baby, including kangarooing, should be a task for both parents, if possible. Preterm born babies benefit sustainably from kangarooing and intensive physical contact with either parent.

Your baby's need for emotional security and stability is particularly strong when they are separated from you, feel frightened, or experience pain. In these instances, your baby will turn to you as their primary attachment figure, requiring a physical and emotional connection.

Separation is one of the major incidents that can trigger your baby's need to attach. It is, however, not the only experience that can activate this need. Other examples include being scared, partaking in painful or invasive medical procedures, frequent interruptions of resting phases, bright lights, loud noises or conversations. Later, in the first years of life, even the first nightmares can prompt a child's need for emotional reassurance through attachment.

Frightening experiences can be caused both by external events or by internal processes. For your baby, it does not make a difference as in both cases they experience an immediate need for attachment. Your baby will want to establish a physical contact with you, their primary attachment figures. Physical closeness is the best way to calm down your baby. In the first months, and as long as they cannot crawl or walk, babies depend on you to overcome physical distance. Especially preterm born babies are often too weak and helpless and thus not able to express their pain and anxiety by crying.

It may be very difficult for you to know that painful procedures are being performed on your baby while you are not allowed to be close to the little patient. However, even though some medical routines cannot be avoided, research shows that you can reduce the emotional and physical distress for your preterm born baby. Being in close and physical contact with your baby just before, immediately after, and, as far as possible, also during the potentially painful treatment helps your baby. Your presence decreases the baby's stress levels and less stress hormones will be released. Your baby's body, and most probably also the mind, recovers faster and, consequently, develops in a healthier manner.

If a longer hospital stay is necessary, it is important that parents spend as much time as possible with their baby and communicate with their baby in different ways. You can comfort your baby in various ways by talking, singing, reading, caressing, holding, consoling, and providing emotional closeness and a sense of safety. Even if kangaroo care is not possible because the baby cannot be taken out of the incubator yet, you can practice all other methods to create and strengthen the bond between you and your baby.

Of course, you cannot stay with your baby night and day without any breaks. This is why it is important that you and your partner also involve other people, such as relatives (e.g. grandparents) or close friends, in your baby's care. Taking turns visiting and caring for the baby ensures that you can take some necessary breaks for yourself. In order to care for your child, you also have to pay attention to your own needs, e.g. by eating healthy food, getting enough sleep, and fresh air. Also make sure that you establish a stable and reliable emotional support system for yourself.

It is comforting for your baby when they start to slowly recognise that the day is structured according to a stable pattern. This includes, for instance, a fixed time span when you are usually present and when you are leaving again, or which parent is normally present at what times. Such reliable patterns give your baby a sense of stability and safety and have a calming effect on their emotions.

Changing caregivers

For babies, parents are uniquely important. Even though your child is cared for by different nurses, the attachment with you is closer and more trusting. You, as the parents, are irreplaceable attachment figures for your baby. After all, the time you spend with your baby is normally longer and more intense compared to the baby's contact with the nurses.

You will cuddle and caress your baby more than the nurses will, even though in the beginning it might not always be possible yet. Kangarooing, for example, is a great intervention to create that special sense of closeness. While your baby is in intensive care, you might have the feeling that you cannot do much for your little one, but there is a special quality to the contact between parents and baby that cannot be provided by nurses.

Besides extensive interaction by touch, eye contact, and talking soothingly (speaking increases bonding as well) with your baby, it is also helpful when the nurses and you jointly wash the baby and change nappies. These care procedures offer a great chance for bonding between you and your baby. In the course of the first year, your baby should develop a strong attachment with at least one parent; this can be either of you. It is important to know that babies do not choose their primary attachment figure on genetic grounds; instead, they choose the person who conveys the strongest feeling of protection and safety.

Research shows that if children experience that their parents are there for them unconditionally and comfort and support them in difficult emotional situations (e.g. after a separation, a fight, failure, pain, insecurity, fear, disappointment), it seems to provide a protective shield for their further development. As a matter of fact, children at the age of 13 who were born preterm but experienced sensitive and emotional parenting behaviour, perform better at school compared to children who did not receive emotional support by their parents.



**“You, as the parents, are
irreplaceable attachment
figures for your baby.”**

The paediatric nurses will, of course, also grow fond of your child. The more affectionately they care for your baby and the better the care is organised (e.g. keeping the number of nurses interacting with your baby to a minimum), the closer the relationship between the nurse and your baby will become. Ideally, there should not be any competition regarding emotional bonds with your baby but rather good cooperation. Parents should openly address any concerns to the nurses while also being aware that their baby can only benefit from loving care by the nurses. When your baby is transferred to another ward or discharged from the hospital, we recommend to give the nurses a little time to say goodbye to the baby. Be aware that the nurses have often spent many weeks caring and worrying for the baby, so it is important for them to get a chance to say goodbye. Do also take your time to say goodbye to (and thank) the nurses yourself. After all, they provided a safe and empathetic "home base" for the entire time your baby had to stay in the hospital, and they gave you support and confidence, especially when you were fearing for your baby's life. Given this emotional relationship, it is more than understandable that the nurses and the whole team in the hospital will be very happy if you visit them later on and show them how well your child developed!

The need for sensory stimulation

During pregnancy, your baby has already perceived sounds coming from you or from the outside; they have noticed phases of activity and resting, sleeping and being awake.

The need to reduce stressful and negative stimuli

During pregnancy, your baby was not only participating in your activities and feelings of joy, but also sensed when you were feeling tense or worried. The sensory experiences in the womb provide the baby with essential information about themselves: the skin serves as a contact organ but also as a type of shield. The inner ear helps the baby to determine their position and their moves; with the help of the sense of vibration they can detect and process vibrations from the outside (e.g. voices, noises) with their whole body. If your baby is born too early, it might have experienced these sensations only partially. To compensate for this lack of sensory experience in the womb as well as the missing experiences of their own body and how it interacts with the environment, it is recommended to include sensory stimulation into daily care routines. The goal is to have the baby make a connection to their early and elementary experiences in the womb. By stimulating the entire surface of the body as well as the muscles, the baby will have a positive body experience and will understand how they can interact with their environment.

The sensory stimulation should be done by frequently and delicately touching the skin. Moreover, the baby can learn additional sensations like tasting, smelling, hearing, and seeing. The baby does not only learn to get a feeling for their own body and how to move, feel, smell, taste, hear, and see, but also to connect these experiences. At the same time, the baby learns and appreciates that you are also interested in these new experiences and that you care about what they feel.

While still in the womb, babies protect themselves against stimuli that can cause pain or unease. Right after birth, this principle turns into a lifelong protective mechanism: by turning away their head, putting their hands in front of the face, closing their mouth or crying, babies try to fight unpleasant stimuli like, e.g., noises and coldness but also heat or pain. Already during birth, the baby is able to differentiate between various flavours, refusing sour and bitter flavours and preferring sweet ones instead. The baby also develops an instinct to avoid or fight unpleasant stimuli and stress and to search for pleasant stimuli, which is an important and potentially life-saving strategy.

Preterm born babies experience more frequently unpleasant and stressful situations caused by painful or invasive treatments, by interruptions of resting phases as well as light and noise disturbances. It is therefore important that you, as the attachment figure, are present to comfort your baby and ease the pain by being in physical contact. Slowly, your baby will make the first attempts of self-regulation to calm down. This includes sucking on a finger or pacifier, yawning, covering eyes and ears, propping up against the bed pad or the walls of the incubator, lifting the hands to the mouth, or putting both hands together.

Summary: To ensure secure attachment with a preterm born baby, it is crucial to consider the baby's individual needs and to give individualized care right from birth. Hospital staff and parents need to learn about the baby's unique needs, understand particular ways of communicating and react to it with sensitivity. This set of methods is generally known as "developmental care in neonatology". One very specific and comprehensive version of developmental care was developed in the United States by Professor Heidelise Als. It is called NIDCAP, which stands for "Newborn Individualized Developmental Care and Assessment Program". NIDCAP proposes to create an atmosphere of physical and emotional closeness between parents and baby, so that the baby can relax and feel at ease. This soothing atmosphere, combined with life-sustaining medical care, offers optimal conditions for reciprocal bonding between parents and baby.

Developmental care in neonatology

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Developmental care in neonatology is an approach that uses a number of different interventions to decrease the stress of preterm and ill babies in NICUs or babies who require intensive and specialised medical care. The objective is to ensure the infant's optimal neurobehavioural development. These interventions include, among others, the control of external stimuli (e.g. activity, noise, or bright lights), specific supportive behavioural techniques, such as the positioning of the baby, skin-to-skin care, or the integration of parents in care activities and in decision-making processes regarding the baby's treatment and care. Developmental care creates a neonatal environment that minimises stress for the baby as well as for parents and healthcare professionals. It reduces pain and provides a developmentally appropriate sensory experience for each individual baby. The approach recognises that each baby is an individual with a distinctive voice which must be carefully listened to and heeded. Each baby must be treated with respect and dignity at all times.

Newborn care is practiced differently in different intensive care units. The same applies to developmental care. However, there are some key principles that are followed everywhere. One of them is the idea of "family-centred care", which stresses the essential role parents play in their child's life. Right from the beginning, you, the parents, are the most important persons in your baby's life. Even if your baby depends on medical care and high-tech equipment, and you might feel that you cannot help your baby at all, your presence, your voice, and your support is crucial. You as parents are the main caregivers together with the team at the hospital.



The second key principle is that your baby has a voice. However, since your baby cannot speak yet, they communicate instead through their behaviour. It is important that you, the parents, as well as the medical staff recognise and correctly interpret your baby's behaviour. Each baby communicates in their own way and everyone involved in the care of your baby, including you, should respond appropriately to these body language signals. This will increase the baby's well-being and make sure that they feel safe in their environment and in the care they receive.

Professor Heidelise Als, together with some colleagues in the United States, studied the behaviour of preterm and newborn babies to understand it and make suggestions for how to respond to it in a creative and sensitive manner. They developed a complete and comprehensive program called "Newborn Individualized Developmental Care and Assessment Program" (NIDCAP). NIDCAP highlights the importance of closely observing every

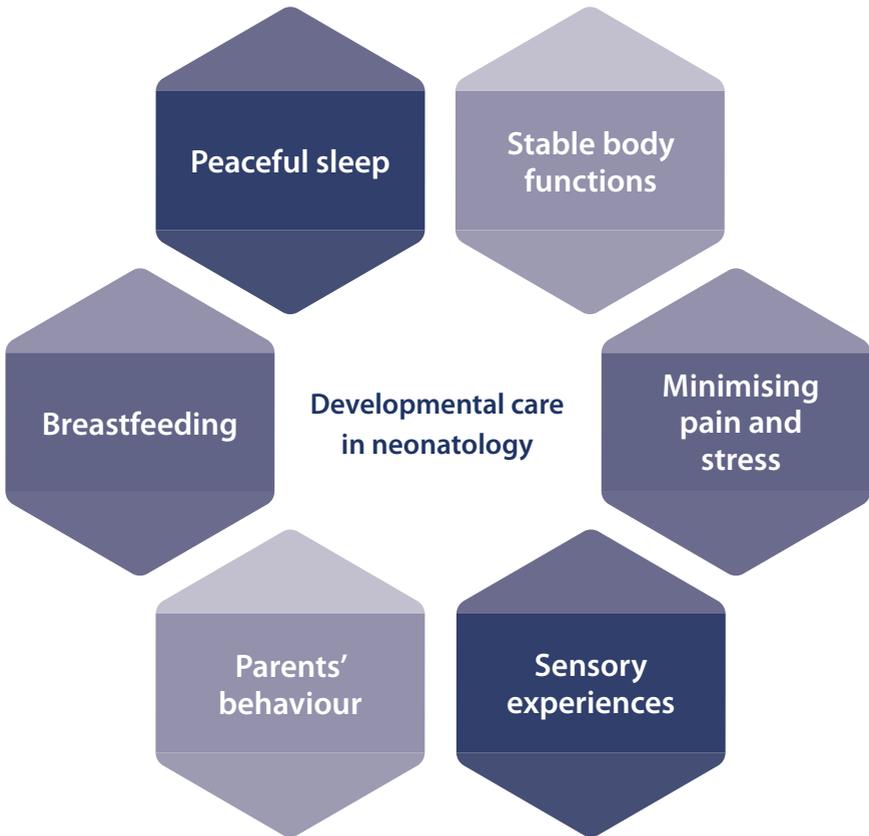
little reaction of the baby, thus helping us to understand and interpret these reactions, and gives advice on how to adjust the care accordingly so that the baby's continued positive development is ensured. In the approach, caring should be a dialogue between the baby and the caregiver, and it starts with understanding the baby's language.

Understanding your baby

As soon as a baby is born, the whole family is full of admiration for this new little person and takes in all the unique features which make them such a special personality. This also holds true for a preterm born and/or ill baby. As a parent, you might feel helpless when your baby is lying in an incubator, connected to life-saving devices. But this observational phase is both extremely important and can even be a pleasant experience as you embark on your joint journey. Consider the time for such observations not as incidental or secondary, but understand it instead as the basis of care that preterm born babies and newborns need for their development. You will soon notice the little changes in your baby's behaviour which tell you how your child feels and you will learn how to react to your baby. As a parent, you usually know your baby better than anyone else does, and you can draw the nursing staff's attention to small changes that show whether your baby feels fine or unwell or which kind of treatment they love. Please let the medical staff know the slightest change in your baby's behaviour.



Developmental needs and benefits of developmental care



The two key factors for early childhood development are the brain and the parent-child relationship. Meeting the developmental needs of preterm born babies on the neonatal ward means thinking about how to create an environment in which the brain develops healthily as well as fostering opportunities for loving contact with the parents/family. Scientific evidence suggests that developmental care can indeed make a positive impact.

The brain develops to a significant extent in the last trimester of the pregnancy. It then triples in size, creating countless active connections between the cells, and it builds those links and information pathways that determine how our brains function for the rest of our lives. Some of these developments are the same for all people (e.g. our ability for language acquisition); some are the result of a unique combination of genetically inherited characteristics (e.g. our voice that, by virtue of its unique characteristics, becomes an acoustic means of identification). Other developments are acquired through prenatal and postnatal experiences (e.g. speech and accent).

A preterm born baby starts with a different set of preconditions than a term born baby that could develop undisturbedly in a healthy uterus. This difference explains the considerable challenges for developmental care in the case of preterm birth.

Stable body functions



In order to develop healthily, the brain requires stable body functions as a basis, especially a stable blood supply with oxygen and nutrients, a stable body temperature, and functioning intestines. The baby needs to be able to store energy; they must adapt to inhaling air with immature lungs as well as to digesting milk with immature intestines. The baby has to adapt to an environment which is far superior to their own level of development. Research has shown that the way we design the environment for a preterm born infant (e.g. light and sound) as well as their daily routine (including daily practices of care such as how the baby is held, carried, and laid down) can affect both positively and negatively the baby's heartbeat, breathing pattern, oxygen supply, blood pressure in the brain, body temperature, sleep rhythm, and oxygen consumption. In addition to the medical care, careful observation and individualisation of care will help the baby to become stronger and more stable and allow them to feel safe.

Peaceful sleep



To develop and grow, the brain needs sleep. From the 28th week of gestation, an active sleep state can already be observed, recognisable by rapid eye movements (REM phases), which is accompanied by a high degree of brain activity and the organisation of nerve connections. Gradually quieter, deeper sleep phases occur, which are essential for growth. It is very important to protect your baby's sleep as much as possible, to avoid interruptions, and to calm your baby in the event of restlessness. Sleep patterns are influenced by sleeping position, light and sounds, hunger, and discomfort.

Another important aspect of developmental care is to pay attention to the baby's evolving body posture. Supporting your baby to feel comfortable in a position which imitates the embryonic posture, as well as consciously aligning and assisting their head, body, hands, and feet, makes it easier for the baby to find movements to feel content and relaxed, such as, for example, putting their hand to the mouth, reaching out, or putting their feet together. This all can help your baby to comfort themselves and cope with the environment or procedure.

Proper positioning can protect your baby from both muscle shortening (which, in turn, affects motor development) as well as head deformation. Both can be the result of a longer, rigid lying position which was never changed and did not provide support and stability. Make sure that, as your baby grows up, you observe the guidelines for safe sleeping. It is important to make sure that your baby's breathing is unaffected while sleeping. This means, for example, to always put your baby to sleep flat on their back on a firm mattress. If they roll over in their sleep, carefully roll your baby back on their back again when you check on them. Also remove any pillows or toys from the cot to avoid your baby overheating and to prevent the toys from impeding your baby's breathing. Make sure they do not get too cold or too hot when sleeping by regularly feeling their stomach or the back of their neck.

Minimising pain and stress



Intensive care includes many uncomfortable or painful procedures. For many years, professionals were divided over whether preterm born babies feel pain or not. Today a large consensus exists that more has to be done to avoid pain for preterm born babies. Even seemingly positive care routines, such as changing nappies and bathing, can be very stressful. Stress and pain cause biochemical processes in the brain which can have long-term negative effects on the nervous system and later influence behaviour and sensory processing. Developmental care has developed a variety of effective non-pharmacological stress-reducing strategies. These include, for example, presence of parents, direct skin contact, letting babies suckle, giving them the opportunity to grab something, letting them support themselves with their feet, building a nest for them, weighing them as well as the reassuring voice of the parents.

As a parent, you take on two important roles: on the one hand, you perceive and articulate your baby's pain and discomfort, and, on the other hand, you create a protective and pleasant environment. Your presence is therefore incredibly important for your baby because you are their advocate as well as their comforter at the same time.

Sensory experiences



The development of the brain is significantly shaped by sensory experiences. In the last trimester of the pregnancy, certain nerve connections grow and form themselves. Permanent neuronal connections arise. This process is influenced by the perception of touch, movement, taste, hearing, and sight. All your baby's senses are functioning well from the 6th month of pregnancy onward. The only exception is vision which is slightly less developed but which will catch up quickly once the calculated delivery date is reached as well as in the time after. One goal of developmental care is to ensure that the baby can experience their senses according to the corresponding developmental stages, even though they may be in the incubator. The best indicator that tells you which stimuli work and which do not, is your baby's behaviour. If your baby reacts with signs of stress,

defensiveness, or rejection, it is likely that the stimulus offered was unsuitable. However, if your baby responds with interest, relaxation, or attention, it suggests that your behaviour (and the stimulus) was appropriate.

Parents' behaviour

Your behaviour can significantly affect the development of your baby. To be able to empathise with your baby's feelings can be a particular challenge, especially if your baby is very young, sick, or temporarily isolated from you. Giving your baby a feeling of security and loving attention triggers hormonal reactions that are important for their further development. In the beginning, you might just want to watch your baby. This is completely normal and by watching your baby, your understanding grows about their way of communicating with you. With the help of the nurse, you gain confidence in your ability to support your baby and to do the things that you as a parent would like to do for your baby. The experience you gain in the NICU can have a lasting effect on the long-term relationship with your baby.



Breastfeeding

Developmental care can assist in feeding your baby because proper nutrition helps your baby grow and have enough energy available to digest the food in the best possible way. Promoting breastfeeding is therefore an essential part of developmental care. Breastfeeding has been proven to contribute to babies' health and development, especially preterm born babies, and also benefits their mothers. Moreover, breastfeeding is a beautiful, enriching, sensual, and social experience for you and for your baby. Even if you cannot breastfeed your preterm born baby (yet), there are other options available to include breast milk in your baby's nutrition. Speak with your doctor or nurse to see if you can, for example, use breast milk to clean your baby's mouth. This can be a way to support your baby's immune system further.



Understanding your baby's voice



What your baby is telling you

Start by observing how your baby is breathing and see how it changes. Perhaps a ventilator/respirator does most of the work first. As soon as your baby breathes independently and their breathing follows a regular pattern, you can observe changes in speed, depth, and rhythm that tell you if your baby feels rather calm, tired, or even agitated. Then watch their skin colour. Initially, many shades of colour are visible because preterm babies have thin skin. Newborns often look very red, but there are also some pale spots, especially around the nose, darker shadows in the area of the mouth and eyes, and there may be some spotty patterns on the body. Once you are more familiar with your baby, you will immediately notice any change that indicates to you that your baby is comfortable, needs rest, needs more comfort, or wants to lie in a different position.

Very small preterm babies often make quick, sudden, and twitching movements, get hiccups, or appear tense in their posture, especially when they feel uncomfortable or overwhelmed. However, this can also happen because of their immature neural developmental state. It is important that the baby is well supported in their environment/bedding so that they are less disrupted by their own movements.



Movement, posture, and muscle tension

Look at how your baby lies and pay attention to whether they look comfortable. Are their arms flexed nearby the body or face and are the legs flexed and relaxed? Or is your baby tense with stretched arms and legs? Is the back overstretched or is the body limp with arms and legs hanging loosely by the side? Does the body adapt to the shape of the underlay or do the muscles look tense? Bent arms and legs are usually a sign of relaxation. Are your baby's movements soft and fluid, do they bring their hands together, pause or even touch their face, press the feet against each other? Or does the baby seem nervous, do they appear startled or agitated? Over time, such movement patterns as well as the degree of muscle tension will tell you whether your baby needs more comfort and support from you or if they are strong enough to do this by themselves. Even the smallest attempt is important for your baby and shows you how strong they already are.

Your baby's facial expression also gives you information about their state of mind. Do you observe tense facial features or is the expression relaxed or lively? Do the cheeks sag when the mouth is open?



Sleep-wake state

Before you start with anything, look at your baby: What are they telling you? Can you detect rapid eye movements when your baby is sleeping? This means that your baby is in an active sleep phase. Give them a moment to rest because this is important for their brain development. You can also notice changes in breathing: for example, does it become slower and more regular when the baby enters a deeper sleep? Does your baby start to open their eyes, especially in response to your voice? Then this may be a good time to make some contact with them to let them know you are there and caring for them. Is your baby restless and wriggly or quiet and content? Does your baby have phases, albeit short, of bright wakefulness or do their eyes have a glassy or slightly frightened expression upon waking up? In the further development of your baby, when they come closer to the calculated date of birth, you will find that they fall into a sleep-wake rhythm that corresponds to hunger and (breast)feeding. As your baby grows older, the time for contact and interaction will become longer as well.

While in the NICU, your baby's sleep-wake rhythm is often interrupted by various activities on the ward. When you are with your baby, observe them calmly. If they sleep, let them sleep for a while. If you notice them waking up, let them know you are with them with your soft voice before touching them.



Attentiveness

As your baby becomes increasingly alert, you will see how they react to your voice. Maybe your baby turns their eyes or their head in the direction of a sound, following slow movements or your face with their eyes. Give your baby the time and space to make contact themselves. Be alert to signals that your baby uses to indicate that a particular contact or environment is perhaps a bit too much at that particular moment. Your baby may close their eyes or turn their face away from you. With these signals they show you that they need a little bit more rest. You can reduce the contact a little. When your baby is ready again, they will look for your face once more.

Tips for developmental care

Planning

Whatever you plan to do with your baby, a little preparation in advance is helpful. Try to consider your baby's routine and plan your activities with your baby accordingly. Schedule them for when they work best for all persons involved, meaning the medical team at the hospital, your baby as well as yourself. Make all the necessary preparations before you start the care procedures so that you can focus on your baby.

Care procedures

Even though you might like to do all care procedures at the same time in order to let your baby rest afterwards, you could overwhelm your baby, especially if they have to undergo many procedures or if your baby is still very sensitive, for example to the environment. Carry out the necessary care of your baby in intervals with, if possible, rest periods of about one hour in-between strenuous events. Take a break during nursing, soothe your baby, and adjust your plans if you see signs of fatigue or discomfort. Then give your baby the opportunity to rest and recover. Be calm, quiet, and soothing; this will transfer itself onto your baby. Your baby should be in the lead as much as possible during care procedures with everyone else adjusting their actions to the baby's cues and signals.

Atmosphere

A calm and quiet atmosphere with dimmed lighting is more comfortable for you and your baby because it makes opening their eyes more pleasant. If you need more light for certain activities, protect your baby's eyes with your hands or a shield.

A helping hand for your baby

Any activity with a small, tender baby is a sensitive task that requires your full attention. Whenever possible, you should seek the assistance of a second person so that one of you can respond to your baby's behaviour signals while the other one manages the task.

Parent-Baby-Activities



Comfort

Even if your baby is very sick and weak, you can give loving comfort. Together with the medical team you can interpret signs that show your baby is relaxed and feels well or they are tense, over-sensitive, and feel unwell. A gentle touch, like placing your hand on their head, can calm your baby. Your hands should be warm and if temperature regulation is a problem, your baby can wear small hats because the hands can have a cooling effect. Maybe your baby likes it when you cover their feet or let them grab your fingers. Learn to differentiate your baby's restful sleep periods from those in which comfort is welcome. Preterm and ill newborns usually like the touch of a hand that simply rests in place. Caressing, especially with small, light movements, can irritate them. Your soothing voice also benefits your baby. Wait and observe their reaction. Preterm born babies often react with a slight delay.

If your baby needs intensive care, they inevitably have to undergo examinations and treatments that can make them feel uncomfortable and stressed. Some parents like to be present during these examinations, others do not. You can almost always support your baby during or after the treatment by gently holding them, calming them down, offering your fingers to hold on to, or by helping them suckle. Talk to the nurse or doctor about what is possible in each instance. Sometimes, the nurse or the doctor may ask you to make some room so they can do their work. But there is always a possibility to stay in contact with your baby. For example, your voice can be very helpful even if you cannot touch your baby in that particular moment. In fact, some treatments are easier to accomplish if your baby is held skin-to-skin or breastfed. Even just a drop of breast milk on your baby's lips or pacifier can help. Rest assured that your baby is not going to connect breastfeeding with a painful experience. There is no evidence for this theory.



Oral care

Cleaning your baby's face and mouth is often the first opportunity to take care of your baby yourself. Your baby should be awake and in a good mood. If you have expressed milk, you can moisten a cotton stick or small cotton cloth and give your baby a new, pleasant taste experience. The taste of breast milk is similar to that of the amniotic fluid, which will be familiar to your baby. Clean the mouth slowly with light pressure on the lips

(make scooping movements). This is more pleasant than wiping, for example, because the mouth is a very sensitive area. Therefore, wait until your baby opens their mouth by themselves. If your baby likes the taste, let them suckle on the cotton stick. Even if you only have sterile water, your baby may try to suck on it.



Feeding

Your next activity might be to help tube feed your baby. The nurse will always double-check if the feeding tube is positioned correctly. Be sure to sit comfortably before starting, as it may become exhausting after a while to hold up the syringe. Watch how your baby's behaviour changes when the milk starts flowing into their stomach. If your baby starts to squirm and gets restless, lower the syringe to slow down the flow of milk or stop the feeding to allow your baby to rest. If your baby is fed with the tube while in the incubator, place your hand on their shoulder or bottom to foster a feeling of closeness. In time, you will also notice when your baby gets restless and needs a break.

Tube food can be digested more easily if given very slowly. The ideal posture is the kangaroo position where you keep your baby on your chest in direct skin-to-skin contact with yourself.

Preterm born babies sometimes like to lick milk drops from your breasts. They develop the skills to coordinate sucking, swallowing, and breathing starting in the 32nd to the 34th week of pregnancy. Breastfeeding can start earlier than bottle feeding because it is safer. It is also easier to let your baby decide when to breastfeed instead of introducing regular breastfeeding times. Even if you have not planned to breastfeed that very moment, you can indulge your baby and breastfeed.

It is difficult for you as a parent to know when your baby can control their food intake on their own. A baby's behaviour is usually unpredictable, and you will probably receive a variety of different suggestions every day from different people. Treat this advice like you would a menu in a restaurant and follow only those recommendations which are closest to you and your ideas. All of this often happens when you feel restless yourself. Sometimes, just when everything is going well, your baby appears subdued and lethargic for a week. This could be because the body is producing more red blood cells or is experiencing a growth spurt.

If you feed your baby with the bottle, then you should observe carefully to make sure that it is enjoyable for your baby. Feeding does not just mean food intake, but also communication and interaction. It can be difficult to position a preterm baby to enable them to drink from the bottle because they often cannot yet muster the requisite muscle tension. Avoid supporting your baby by the neck while their arms are dangling. Instead, lay your baby on the side with a pillow on your lap, head higher than the feet, and support their back. The grabbing reflex is connected to the sucking reflex. Therefore, please give your baby your fingers to hold on to. The overall goal for any feeding experience should be that it is pleasurable and effective in the context of a loving parent-child interaction.



Changing Nappies

In the beginning, watch how the nurses change the nappy. If you want to join in, start by putting on the fresh nappy and soothing the baby. The following times, step in a little earlier each time until you eventually feel secure during the entire process. In general, nappy changing can be tiring and uncomfortable for young babies, and they often prefer to lie on the side. Never lift your baby by the legs to access the bottom. You will see that your baby relaxes and the bottom can be cleaned best when holding their feet together, sole to sole, bending the knees slightly. Wrapping a small sheet, blanket, or scarf around your baby's arms and shoulders also helps to keep them supported and calm. If you are unsure, do not hesitate to ask for help or ask to do it together in the beginning.



Weighing

You can also participate in weighing your baby. With your help, the nurse will easily be able to weigh clothes and nappies one by one and then put your baby on the scales. You can hold your baby while the nurse changes the bedding.

It is always a great pleasure to experience how fast your baby gains weight and grows. It often turns out to be enjoyable to go straight from weighing to kangarooing. This means you do not have to put your baby's clothes on and take them off again several times throughout the day.



Cuddling and kangarooing

You may be able to cuddle with your baby from day one and use the “kangaroo method”. Even if your baby is artificially ventilated, “kangarooing” may be possible, although this sometimes also depends on the rules of the hospital and the neonatal ward. In these cases, it is best to discuss the possibility of “kangarooing” with the medical staff.

Following this method, the baby lies belly-down on the chest of a parent in direct skin-to-skin contact with them. The parent’s body heat provides comfort which allows preterm born babies to relax the best. It is also a unique method to strengthen the parent-child connection and has also been proven to support your baby’s development.

“Kangarooing” can already be done directly after giving birth in the delivery room. You can also start with it early in the neonatal ward. This way, you can already support your baby within the first few hours and days of their life. Kangarooing may need some preparation and can depend on your baby’s condition. How well and secure you feel also plays a role. Depending on the conditions, “kangarooing” can be done several hours daily. Your baby will tell you whether they are ready for body and skin contact and for how long.



**„The kangaroo method
is a unique way to
strengthen the parent-
child connection.“**

The kangaroo method offers you, as a parent, a unique opportunity to provide essential care for your baby. In the beginning, it may take some getting used to, but the sooner you cuddle with your baby, the faster you establish the necessary foundation for comfort and confidence. Kangarooing stimulates the distribution of oxytocin. This neurohormone, which is also called the “bonding or love hormone”, has many positive side effects: it helps you to build a bond with your baby and also stimulates milk production. Your baby will be kept stable and warm and will sleep well. Wear light clothing with a button-down front and take advantage of kangarooing whenever you can (note: use the toilet beforehand). In some countries, babies are cared for around the clock using kangarooing.

To take your baby out of the incubator can be challenging. The paediatric nurse will do this for you in the beginning; later you can do it by yourself. When the baby is on your breast or chest, ask for a hand mirror to watch your baby’s face. If you would like to include, say, grandparents and siblings in the kangarooing activities, discuss with your medical team whether this is possible and how it can be done in a way that benefits your baby.



Bathing

Proper hygiene is very important, especially for your baby on the neonatal ward. The nurses will focus on this on a daily basis. Feel free to discuss with the medical team whether you can take over responsibility for your baby’s hygiene. It is important to keep in mind that during all hygienic procedures, your baby and their behavioural cues should serve as guidance. If your baby indicates through their behaviour that it is all a bit too much, you should take a break before continuing. The nurses will support you.

In the beginning, your baby is washed in their bed. At first, you can do this together with your nurse by using warm water and carefully cleaning all skin folds in the neck, behind the ears, under the arms, and between the legs. Later, you can do this on your own. Watch your baby carefully. They will tell you if they are ready to be washed. The first bath is an important event for parents. It usually happens when your baby shows you they are ready for it, e.g. when they can already sleep in the warming bed and will soon be released home. If necessary, have the hospital staff use a doll to show you what to do. Your paediatric nurse will be at your side to make sure your first bathing experience is a success.

Bathing is also another wonderful opportunity to get to know your baby better and to learn more about them and what they like and dislike. If you want to record a bathing video, plan ahead of time. For babies, bathing can be a strenuous affair and some feel better when wrapped in a towel during their first bath. Make sure your baby’s feet can always touch the inside of the bathtub, which will give them comfort and confidence when stretching out.



Going home

For some parents, it is hard to believe that their baby is finally coming home and often preparations are postponed until the last minute. This is usually the time when you need to be in the hospital often to develop a nursing routine. Therefore, discuss in advance with the ward team when your baby will be able to go home. This can be between the 34th and 40th week, but also later, depending on how your baby has developed. It is best to prepare everything that is necessary in advance, i.e. a few weeks before the expected date, because the discharge date may be earlier than expected.

As soon as you leave the hospital with your baby, you should be familiar with their proper care in every respect. Ideally, you had the chance to spend the night together with your baby in the hospital before going home. Nevertheless, you will be surprised how much time and attention such a small but rapidly developing baby requires. During this time, your baby is extremely dependent on you to have the sensory experiences needed to feel secure enough to navigate this new world. This means your baby expects to be carried and held by you a lot. This will not spoil your child – it is completely normal. It is just as normal for your baby to wake up often during the night. This gets better after about three months when the baby's biorhythm is more accustomed to the day-night cycle.



Practical implementation of developmental care in neonatology

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In this article, we focus on the concrete implementation of supportive developmental care inside a NICU and depict the ideal ward. Although reality may often be different, we consider it useful to describe the ideal as accurately as possible. This will help to further its implementation in many different areas.

Environment

- the NICU is easy to locate in the hospital
- parents have unimpeded access at any given time
- inside the ward, a family-friendly atmosphere prevails; there is enough space for every baby and their parents
- parents have the opportunity to be 24/7 with their baby, if they wish to

The child's space

- all necessary materials and devices are stored in a way which does not obstruct access to the baby
- per child, there are two comfortable seating options available, one of these also for lying down
- practicing extensive kangaroo care is possible
- parents can decorate their baby's space if they wish to, for example with photos, stuffed animals, cuddly blankets, and pictures of siblings

Lighting

- every incubator can be covered with dark blankets, preferably with a little window for observation
- the lighting should always be indirect (e.g. a spotlight facing the ceiling)

- for every baby's individual sleep phase, the room should be as dark as possible and should only be dimly lit during the waking period (curtains, blinds, no direct sunlight)
- during medical procedures that require bright lights, for example during blood sampling, the baby's eyes are covered and direct light is avoided
- prior to phototherapy, an eye protection device is fitted and the baby is put into a comfortable position
- after phototherapy, the transition to normal daylight is gradual

Noise and sounds

- no items are stored or placed on top of the incubator (sound is amplified through the acrylic glass enclosure)
- the medical staff speaks softly with the baby; the same applies to conversations among each other, with parents, and visitors
- all staff members wear shoes with soft soles; padded garbage bins are used everywhere
- all doors (incubator, cabinet, etc.) are opened and closed quietly
- all packages and packaging are opened outside the ward
- the staff works in a quiet and forward-thinking manner
- there is no radio in the NICU
- all monitors are set to minimum volume; vibration alarms should be used where possible
- all phones are set to minimum volume; phones should be set to vibrate where possible; phone calls are preferably made in a separate room
- noise level indicators are used for sensitising staff and parents
- visits and shift changes take place in another room and not directly next to the baby
- every staff member should behave as if they were in the bedroom of a very sensitive baby

Odours

- no harmful or unnatural scents are used; no perfume, no hairspray, no nicotine
- to minimise the strong odour of hand sanitiser, foresee sufficient drying time
- to enable the baby to recognize their parents' scent, parents are encouraged to bring a small blanket which they themselves have carried on them for a certain time
- frequent and continuous kangarooing is encouraged because the recurring familiar scent has a calming effect on the baby
- kangarooing should take place without a bra, as the nipples emit a stimulating scent for babies

Ward atmosphere

- the staff creates a calm and intimate atmosphere in the ward and maintains it at all times for parents and their babies
- even in the case of an emergency, the workflow is calm and level-headed; within the team everyone cooperates and is supportive in order to maintain the positive ward atmosphere
- other people are asked to respect the calm ward atmosphere as well (e.g. exuberant and excited relatives)

Visual and auditory stimulation

- all visual and auditory stimuli are adapted based on the baby's facial expression
- what the baby likes or does not like is observed individually
- high-contrast visual stimulation is only offered when the baby is awake and receptive
- new visual stimuli are introduced slowly and step by step
- small speakers are installed in the incubator to play the familiar voices of the parents whenever they cannot be present themselves; however, the volume must be set to low
- visual and auditory stimulation is discontinued when the baby is no longer receptive

You can position your baby comfortably with the help of different furs, little nests, and hammocks. If your baby is lying in the incubator, you can tuck them in with thin blankets.



Positioning aids

- positioning aids are used individually and adjusted according to the preferences and needs of each baby
- different furs, little nests, and hammocks are available
- thin blankets are available for tucking in the baby in the incubator
- there is an option for co-bedding
- frequent kangarooing (skin-to-skin contact) is encouraged and parents are thoroughly supported in the process (comfortable resting position, legs in an elevated position, blankets if necessary, hand mirror)

Clothing

- parents can bring the baby's own clothes
- only small fitted nappies are used
- in order to enhance their own body perception, preterm born babies are temporarily dressed with a fitted body, hats, and socks

Aids for self-regulation

- in addition to an adequate position with protective barriers, resources to help with relaxation are always available (positioning rolls, blankets)
- in order to enable every baby to self-regulate and provide comfort for the baby during and after diagnostic and therapeutic interventions, various resources are available, e.g. opportunities to grab and hold something (comforting blanket, small swabs, the parents' fingers) as well as items to suck on (pacifiers, cotton swabs, their own hands)
- parents can comfort the baby through direct skin contact; if they are not available, with the parents' permission, a trusted person (relative, medical staff, friend) can give kangaroo care instead
- parents are encouraged to help their baby to calm down in stressful situations



Medical equipment

- the aim is to provide the baby with the highest possible degree of comfort, even during medical procedures
- a heated cabinet is available for clothes and nappies
- breathing aids are carefully fitted, without causing any pain
- feeding tubes, catheters, and peripheral venous catheters are used in appropriate sizes and are attached in a way which does not cause any additional strain
- during phototherapy, soft eye protection is available in adequate sizes for the baby
- an additional mobile heat lamp has proven advantageous during many medical and care procedures (venepuncture, weighing)
- the staff uses a mobile unit and warm gel during ultrasound examinations
- an incubator with enough space for two babies is always held on standby to enable co-bedding at any time
- the ward primarily uses incubators with integrated scales and x-ray trays

Caring for the Baby:

Making contact

- in order to accurately assess the baby's condition, you always approach them from the front and pay particular attention to their face
- the facial expression of every baby helps you to assess their mood, whether they are happy or unhappy
- while approaching the baby, recall the last encounter the two of you had
- the intensity of contact is adjusted to everyone's individual pace
- after a friendly verbal greeting, you can perform a ritualized individual welcoming touch; this includes, for example, holding the baby's head and feet for several seconds
- once contact between you and the baby has been established in this slow and respectful manner, the baby is well prepared for upcoming procedures because they had the chance to develop a sense of security first

Positioning and holding

- during positioning and holding, the baby is always held in a physiological and natural position, which applies to supine, prone, and lateral positions
- when the baby's position is changed, their arms and legs are wrapped in warm blankets and brought into a relaxed, flexed position
- all passive motions are performed while fully focused and with the slow pace of the baby in mind
- prior to changing the baby's position, all steps are carefully planned and necessary materials are prepared beforehand (laying warm nappies on the scale, switching on the heat lamp)
- during a position change, the baby is not left alone; usually two persons stand on each side of the incubator directly next to the baby
- while picking up the baby, the head is put in centre position, slightly bowed; forearms and hands envelop the baby in a way which mimics the protective womb

- additionally, the parents' hands or those of the medical staff provide an extensive and protective boundary for the baby
- the baby's need for sucking and touching is respected and met with appropriate options
- the staff is always conscious of the baby's positioning, also during position changes and between interventions
- after repositioning, hands are carefully taken off the baby, slowly and one after the other
- after every position change, make sure the baby is calm and relaxed so they can fall asleep peacefully
- the objective of an effective resting position is low energy consumption which, in turn, leads to longer and more comfortable sleep
- parents and nursing staff support the baby by holding them in a protective way and offering affection and comfort

Transportation

- during the time in the NICU, parents are encouraged to support their baby as much as possible and to directly assist during each transport
- for long distance transport, kangarooing is the gentlest method because it ensures continuous skin-to-skin contact between baby and parent
- transporting the baby while kangarooing provides the best possible protection against vibrations and strengthens the bond between parents and baby
- during transport in an ambulance, the baby is secured while lying on the parent's chest; this happens with the help of an adequately sized blanket (over 400cm x 50cm or 160in x 20in) which is wrapped around the parent and the baby
- following standard procedures, the parent is secured on a stretcher with a safety belt; to secure the upper body, a safety harness made from braces/suspenders is used
- if transport becomes necessary even though the baby is still in the incubator, the baby is laid down in a supportive and calming position with protective barriers on all sides

Breastfeeding and feeding

- every feeding is performed in a warm and pleasant environment
- to consciously experience feelings of hunger as well as fullness, the baby should be awake when being fed
- attempts are made early on to familiarize even those babies born very preterm with breastfeeding; this strategy can be combined with slow tube feeding at the same time until the baby has learned how to breastfeed without assistance; various tools can be used to help them (finger feeder, breastfeeding supplementer, cups)
- if tube feeding is necessary, it is done slowly, with many breaks throughout the feeding process; tubes with a small diameter are used in order to prevent the baby from swallowing too much food too quickly
- during tube feeding, the baby lies as often as possible skin-to-skin on the mother's chest and is able to smell and interact with her breasts
- during tube feeding in an incubator, the baby can suck on a pacifier, a cotton swab with breast milk, or is able to interact with their own hands
- during tube feeding, the child is not left alone; parents and nurses caress the baby, signalling comfort, affection, and protection; the baby can cuddle comfortably with their parents or a nurse
- after the tube feeding phase, the baby is held and calmed, facilitating a smooth transition into sleep
- from the beginning, the hospital staff includes the parents in the feeding process to encourage them to take on the role as providers and protectors

Nappy changes

- in preparation of an upcoming nappy change, gather all materials in advance and ready the place where you want to change the baby (warm temperatures, appropriately sized nappies)
- before you start the nappy change, lay the baby on their side and slightly flex their arms and legs to make sure they are comfortable
- lift the upper leg slightly and clean the bum while both legs remain flexed
- removing the used nappy and putting on a fresh one is performed in this position as well
- do not pull the baby upwards by the ankles while they are lying on their back because this impedes breathing and abruptly raises blood pressure in the brain
- while learning how to change nappies properly in a lateral position, parents are supported at all times by the hospital staff

Bathing

- only bathe the baby if they have enough energy for this activity
- the bath takes place in a warm room with dim lighting
- the water temperature is 37 degrees Celsius / 98.6 degrees Fahrenheit
- wrap your baby in a cloth or blanket (e.g. a cotton nappy) and gently cradle them
- the first thing with which the baby's feet come in contact is the edge of the bathtub; then lower the baby slowly into the water until the shoulders are covered with warm water
- besides small bathtubs, Tummy Tubs, i.e. special buckets for bathing babies, are particularly suitable because their shape is inspired by the uterus, which calms the baby down due to the familiar and protective shape
- frequency and duration of baths are determined by the baby's energy levels, sleep cycle, and feeding times

For bathing, the optimal water temperature is

37° Celsius

or 98.6° Fahrenheit.



Planning and supporting medical measures

- during all necessary procedures, you must prevent overstraining the baby
- scheduled actions consider the baby's sleep cycle and energy levels, and medical interventions are adjusted to the baby's condition
- in order to prevent pain, the baby receives a 20 percent sucrose solution two minutes prior to every intervention; pain management is most successful when the baby can also suck on a pacifier
- you can help prevent pain by protectively holding your baby with both of your hands while they are lying in a bowed position
- after diagnostic and therapeutic measures are finished, the baby is only left alone once they are calm and comfortable again
- parents should bring stuffed animals to convey a sense of security and to provide a calming atmosphere for the baby and themselves
- during consultation services with other doctors (e.g. the ophthalmologist), the calm atmosphere of the ward is maintained

Encourage awareness and avoid stress

- the baby's waking phases are used to introduce different stimuli
- while introducing new stimuli the baby is continuously monitored to prevent overstraining
- if the baby makes eye contact, respond with a loving gaze
- speak to the baby in a calm and quiet manner; spatial boundaries have a calming effect and reduce stress
- if you observe stress-related facial and motor expressions (erratic eye movement, anxious and panicked looks, legs and arms stretched upwards, fingers spread apart, yawning), react accordingly
- when the baby cries, comfort them immediately
- do not leave the baby alone when they are agitated



The parents' role

- do not think of parents as visitors, but rather see them as specialists who are indispensable for the baby's care; they are essential partners for the entire medical staff on the ward
- parents are granted easy access to the ward at all times without any time limitations (24 hours a day)
- parents should feel that they are qualified to take care of their baby every day; share with them as well your joy over their baby's developmental progress
- the medical staff and families always treat each other with respect and appreciation because this attitude also benefits the little patients
- parents always receive complete medical information regarding their baby
- involve parents in every decision

Tips for skin care for preterm born babies from a dermatologist

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A baby's skin is completely developed only after the 34th week of pregnancy. This means that the skin of preterm born babies is characterised by functional and structural immaturity and that babies under 1,800 g (about 4 lbs) are therefore cared for in incubators.

Apart from sepsis and pneumonia, superficial skin injuries like pressure sores, which most commonly develop on a baby's head and heels, are some of the most frequent complications. As a precaution, you should always use hydrocolloid dressings to protect the baby's skin; if these dressings are transparent you can also check for skin anomalies at any time.

Skin care

In this early phase, the staff in the neonatal ward will attend to the skin care of your preterm born baby. Nevertheless, you should be involved in caring for your baby from an early stage on. Regular skin-to-skin contact with your baby, by cuddling or laying on your chest, is an important element which positively influences your baby's overall well-being. This practice is called "kangaroo care" and has its roots in Colombia, a country where preterm born babies rarely have access to an incubator. Studies have shown that kangaroo care improves your baby's metabolism and respiration. Even the WHO recommends practicing this extremely beneficial skin-to-skin contact as early as possible and for a sufficient amount of time (meaning at least one hour a day).

Navel care and bathing

Navel care is performed by placing a dry swab around the navel, between the skin of the tummy and the navel itself, until the rest of the umbilical cord falls off on its own. Antibiotic ointments or creams are not necessary. In many neonatal care wards, preterm born babies are bathed as soon as the navel has completely dried and their heart and lung functions have stabilised. At the latest after discharge from the hospital, you can care for your preterm born baby as you would for a full-term born one. Considering skin physiology, bathing your baby is preferable to cleaning them with a flannel or washcloth because it does not harm the baby's skin. What is more, bathing offers significant psychological advantages. First of all, it encourages body contact between you and your baby. Moreover, it generally calms the baby down. You can bathe your baby two to three times a week with each bath lasting between five and ten minutes.



The water temperature should be similar to the baby's body temperature, ranging from 37° C (98.6° F) to 37.5° C (99.5° F). Use a pH-neutral bath gel with additional skin-caring ingredients. During bathing, you can cover the baby's whole body with water, except for the head and neck. Afterwards, wrap your baby in a dry towel and carefully dab the skin dry.

If your baby's skin shows signs of dryness, immediately apply a mild cream or lotion based on a water-in-oil emulsion (a W/O type cream). Babies love the slow and careful application of lotion on their skin.

Furthermore, regular skin care is recommended for all newborns with congenital dry skin. The product you use should be free of perfumes, scents, preservatives, and parabens.

Nappy area care

Your child's nappy area needs special treatment. Perform nappy care after every nappy change or, at the very least, after every bowel movement. Clean the bum with lukewarm water and – especially in the case of rashes – with a plant-based oil which protects the skin at the same time. You can treat sore skin or rashes with a zinc-based rash cream. The cream's consistency should not be too solid so that you can massage it easily into the skin. If you measure your baby's body temperature rectally, always put ointment on the tip of the thermometer to protect the baby's sensitive bum.

Holding and carrying

You have to keep in mind some things while holding and carrying your baby: the baby's head should always be supported since babies cannot yet hold their head up on their own. Watch out for arms and legs as they should not get stuck or wedged in anywhere. As a parent, it is also important to take care of yourself: a straight posture while lifting and carrying your baby also protects your own back.

Carrying your preterm born baby while having direct skin-to-skin contact, following the principles of kangaroo care with appropriate equipment, boosts your baby's psychosocial development.

Only being there yourself is better – virtual visits in the NICU

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Preterm born babies are the patient group with the longest staying times in paediatric hospitals. For most families, the situation in the NICU is deeply taxing. On the one hand, families feel helpless and, on the other, construction limitations do not allow for prolonged stays in many hospitals.

Despite the 1989 UN Convention on the Rights of the Child demanding that no child should be separated from their parents against their will, as well as the recommendation from the European Association for Children in Hospital (EACH) to offer suitable rooms to accommodate parents, NICUs around the world struggle to fully comply with those demands. Even though a paradigm shift has taken place in neonatology in recent years, and unlimited visiting hours are now considered an international standard, a lack of space hinders optimal infant- and family-centred developmental care for preterm babies. For times in which parents are at home or on the go and cannot be physically near their baby, internet-based video streaming services offer the possibility of “virtual visits”. This visiting alternative boosts parents’ autonomy and competence levels. Besides reducing stress for families (“Before going to bed, I look quickly at my son. If I see him lying there peacefully, it calms me down.” – quote from a preterm mother), positive effects on siblings, who have to deal with the frequent absence of their parents, have been noted.

On admission, or rather within the first days of arriving at the ward, parents are introduced to the video-streaming service. Those parents who are interested in using this service receive a comprehensive introduction on how to use the system. Over a secure online platform, parents now have the opportunity to watch over their baby. To use this additional service, parents can access a safe online platform with an individual password for each livestream. The platform can be accessed from every device (smartphone, tablet, PC) with an internet connection. Due to data protection laws as well as privacy laws, the stream exclusively transmits encrypted image data. Audio signals are not transmitted and image data is not stored. The bed camera is pointed in such a way that personal and health data (e.g. on corresponding monitors) cannot be viewed on-stream. The integrated solutions for video streaming in hospitals, which are currently available on the market, must be adjusted to comply with your country’s data protection regulations. Video streaming is not going to solve the building restrictions found in many NICUs worldwide, but it is an additional step towards integrating parents into the neonatal care team and a further step towards providing complete transparency of medical treatments.

A mother's experience

Our son was born too early and had to be treated at the NICU of the Bonn University Hospital for a few of weeks. My husband and I spent each and every minute of our spare time by his side. But there were times we had to be separated from him. We were offered to try out a new service: virtual visits. A web camera was mounted above his incubator and streamed live images. That way we could see our son around the clock. Especially for my husband, who had to return to work again after two weeks, it was a welcome tool because it allowed him to watch our son during lunch breaks.

For us, personally, the camera meant that we could see our son whenever one of us could not make it to the hospital, like in the morning immediately after getting up or even after returning from the NICU. It was also wonderful to be able to show him to our family and friends via live stream and it calmed us down, seeing our little one at home in-between visits or while on the go. However, it could not replace the direct physical contact, the caressing, cuddling, and smelling. Even though we knew that we were at least virtually connected to our son with the help of the web-cam, returning home still always felt difficult. Before leaving the NICU, we always checked that the camera was on and that our son was in the frame.



The first time at home

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Finally, the time has come! The hospital discharge is in sight. You soon will be going home with your baby.

This is exciting, of course. Apart from happy, most parents also feel a bit uncertain about how things are going to be at home. This is normal. In most cases, the discharge date is even prior to the expected due date. You have a preterm baby and you are a preterm parent. Instead of a calm preparation period of nine months, you have had many turbulent weeks. In your world, many things were (and are) very different.

Asking questions

Prior to discharge, you should have the opportunity to ask all of your questions and to discuss your baby's developmental process so far, ideally in the course of a proper discharge conversation. You should specifically request such a conversation if it is not offered to you. It should take place at least one day prior to discharge and should be set up a few days in advance so that you have enough time to prepare important issues and questions that you want to address.

The discharge conversation should be held in a calm atmosphere without a limit on time. Ideally, you meet in a separate room and talk between 30 to 90 minutes. The conversation should include at least one member of the medical and one of the nursing team. You, as parents, can also decide whether to include any other trusted persons, e.g. grandparents, midwife, social worker, siblings, etc.

Everything is new

You are home at last – a big change for everyone. Noises, smells, and lighting conditions are suddenly very different for your baby. The bed feels different. During nappy changes and washing, a whole set of new stimuli influences your baby. The only things that are familiar are your voices, your touch, your smell as well as the way you hold and caress your baby. This conveys a sense of security to your steadily growing baby. You should try to create as many intimate moments as possible, and of course you are allowed to kangaroo with your baby at home as long as possible, exactly like you did in the hospital. You can cuddle with your baby while fully dressed – though it is more relaxing and intimate if you stick to the original version of direct skin-to-skin contact in a sufficiently warm environment.

For most families, it is a positive experience when they do not schedule too many visits and appointments in the first few days or weeks, leaving more time to rest and relax. Your baby will be happy about change and pleased with experiencing and learning new things – but they need an everyday routine with recurring rituals in order to feel secure and thrive.

Peace and patience

Watch your baby for signs of being overwhelmed. They often express this feeling by looking away, appearing sleepy, yawning, or overstretching. Sometimes babies spread their fingers or change the skin colour of their face; sometimes they are cranky and difficult to calm down. In these situations, you should reduce irritating ambient stimuli for your baby and instead create a surrounding which is as quiet and as peaceful as possible so that your baby can calm down and regenerate. Keep in mind that adjusting to a new environment takes time.

To make feeding at home a complication-free process, there are two essential prerequisites: enough time and patience. Feeding becomes easier for you and your baby when you sit down comfortably in a quiet environment and make sure you are not disturbed. The best time for feeding is when your baby is awake, alert, and calm. Position them in a lightly bent body posture as well.

Breast milk is certainly the best nutrition you can provide for your baby. Your attending midwife can help you out with numerous pieces of advice when it comes to doing this at home. Of course, you can also be a good parent if you use a special formula for preterm babies instead. Take your time when it comes to feeding, properly observe your baby, and plan for a few breaks during each meal. Feeding should not become a stressful coercive measure but rather a delightful experience.

Help and advice

During the first few weeks at home you will probably get lots of different advice, sometimes even without being asked. The easiest way to deal with this is to hear out every recommendation and to remember that they are all given with good intentions. Afterwards, you can evaluate these suggestions and decide which you will adopt and which are unsuitable for you. Solely you as the responsible parents make these decisions.

Every family is different and, hence, no idea or action is guaranteed to work well in every single situation. You decide what is best. It is helpful if you agree with your partner in advance what your aims and ideas are. If this is your first baby, the entire family has to adjust to this new situation, especially your own parents who have to accustom themselves to the fact that you yourself are a parent now, not only their child anymore.

Parents with preterm born babies have diverse tasks which require a lot of strength, especially as a breastfeeding parent. In the beginning, concentrate on essential tasks and reduce the energy you put into other things, like household or workplace related chores and responsibilities. If possible, ask for help: family, friends, or professional household help. Try to sleep when your baby sleeps – you are also awake at night when your baby needs you, after all. Allow others to help, treat, and pamper you, when offered, without feeling guilty. You can even drop off your baby once in a while to meet up with friends to catch up and relax. These activities benefit you as well as your little one because they enable you to re-energise. Taking breaks is important.

Spoiling little children too much is often frowned upon. This definitely does not apply to the time at home with your preterm born baby. As parent, one of your most important tasks is to pamper your baby. Children need this indulgent love in order to grow and flourish, both physically and mentally.

Of course, you should not completely sacrifice yourself. You are also entitled to rest and breaks – you need your strength and energy for a long time ahead. Not all your child's wishes and needs must be fulfilled immediately. Your child can handle waiting for a little bit.

Nowadays, professionally organised follow-up care can be found in many cities, which makes your first weeks and months at home easier. It is often possible that the same people you already know from hospital also take care of you and your baby at home. This makes the transition a lot easier.

If you do not find yourself in this lucky situation, you can get help from a variety of other places and people: the internet, hotlines, local contacts like paediatricians and midwives, or early intervention programmes. Another source of help is, of course, the paediatric hospital in which you were cared for. On the ward, there is always someone available, no matter the time, whom you can consult via phone. Many parents also report that it was particularly the contact with other preterm parents which helped them because the parent community empathised with and understood their situation more than anyone else.

Living at home

If you already have one child or several older children, these siblings often need more affection and support in the beginning, so they can better adjust to the new situation. They want to feel that their parents are still there for them – even if a small baby joins the family. This transition is often painful and takes time.

Once you get home, you can take a walk with your baby, initially shorter ones, but you can increase the distance as your baby gets older. Most families use a stroller but you can also use a baby sling, weather conditions allowing. These colourful slings are made by a few different companies and most preterm born babies feel very comfortable in them.

You can also use these different carrying techniques at home. You have significantly more freedom if you do not have to use your hands to carry your baby. Furthermore, your baby feels closer to you for a longer period of time and enjoys this type of physical bonding.





The “right” age

People will often ask you: “How old is your baby?” Do not forget that when they ask this question, people assume that your baby was born after 40 weeks of pregnancy. However, if your baby was born three months early, they are actually younger; considering the circumstances of preterm birth, your baby is really only one month old. This is called the corrected age, for which you use the calculated birth date.

The corrected age is used when assessing the baby’s psycho-motor development in smiling, grabbing, sitting, crawling, running, and speaking. This is also the case for evaluating the baby’s weight, height, and head circumference as well as when determining the introduction of supplementary food.

So, if the question comes up during a playground visit or while shopping at the local bakery, simply use the corrected age. This saves you from inappropriate questions and makes comparing your baby’s growth and development with other infants easier. The actual age is used solely for vaccinations – and the first vaccination (at 60 days old) is often already given at the hospital.



Loving care

All of these suggestions should make your first time at home easier and give you ideas for your everyday life. In order to continue your baby's positive further development, building a tight emotional bond is particularly important. Maybe you already feel this special bond whenever you watch your baby in their sleep, hold them in your arms, or cuddle with them. This bond is going to grow and prosper in your everyday life; the normal daily care routines contribute to it, whether it is nappy changes, bathing, or body care.

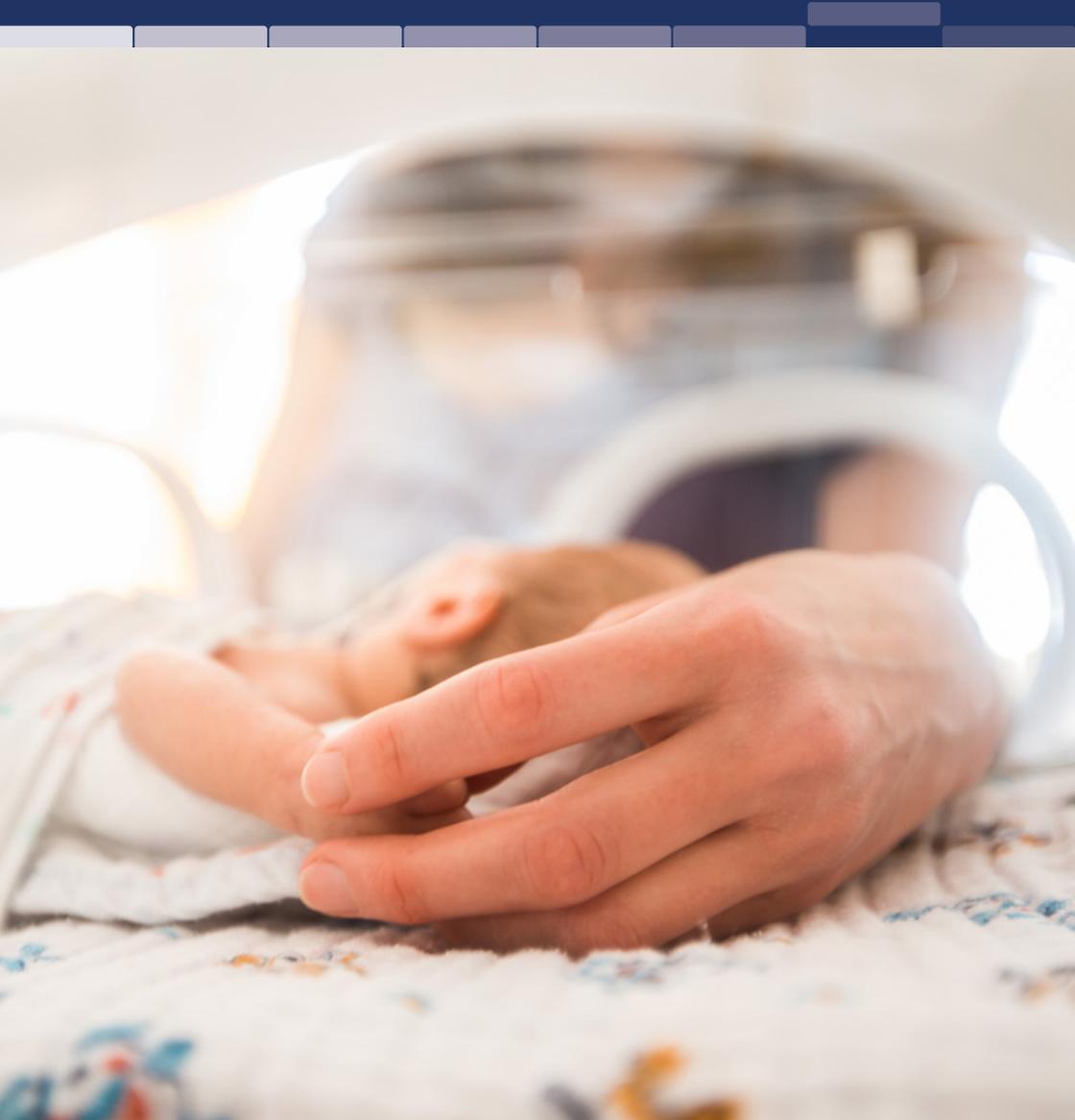
When you are changing nappies or clothes, cherish these moments and make the most of them. Watch your baby carefully and communicate with them. You can quietly sing or talk to your baby, you can laugh with your baby or simply lovingly observe them. Do not let yourself be distracted: give your baby your undivided attention and your entire focus. Open yourself to communicating with your child and, over time, learn your baby's facial expressions, sounds, gestures, and motions. Lovingly touch and caress your child, again and again, and take as much time as you can to make, for example, nappy changes a pleasant experience for both of you.

If you are bathing your baby, the primary goal is to create a comfortable atmosphere, establish communication, create new experiences in a familiar element – not the cleaning part. You may get to know your baby from a completely different side, experiencing new things with them together, exploring a little water adventure. Bathing can take place in a calm and relaxing way, or can be more active and livelier – carefully try out new things with your baby and invent an imaginative game together.

“Your love and closeness play a major part in your baby’s development.”

It should make both of you happy. Bathing in a baby bathtub (e.g. a Tummy Tub, a special bucket for bathing babies) is a more enjoyable experience for most preterm babies than bathing in a regular-sized one. Touching the tub walls with their little hands, feet, and their back, evokes for many babies the same feelings of closeness and comfort they had in the womb. Often, they even fall asleep while bathing. Your baby is going to love it when you affectionately care for them, even after bathing and drying. Provide a sufficient amount of warmth and jointly experience a massage. In the beginning, you may just massage your baby’s arms and legs while they are lying on their back. Later, you can try belly and back massages as well as other positions with your baby lying on the side and belly. Avoid poking your baby with your fingers; instead, try massaging them by using the entire palm of your hand. Most babies feel more comfortable this way because it is similar to the complete covering they experienced in the womb. You can care for your baby’s delicate skin by using creams and lotions as well as massage it with the help of natural oils. Over time, you can massage more intensely to stimulate your baby’s sensory system and sense of their own body and its movements (also called proprioception). Take a break in regular intervals and observe your baby’s behaviour. Only continue if they do not show any signs of distress and clearly signal that they are well, for example through their rosy skin, focused gaze, relaxed facial expression, and calm motions. Enjoy those moments of loving care together without the pressure of time and get to know each other better and better.

Further information



NIDCAP® (Newborn Individualized Developmental Care and Assessment Program)

In the context of developmental care, the term “NIDCAP®” is often used. This special kind of care is based on an extensive programme for individual developmental care and assessment of newborn babies and requires an intensive training which lasts one to two years. NIDCAP® (Newborn Individualized Developmental Care and Assessment Program) was developed in 1984 by Heidelise Als, a German professor and neuropsychologist at the Children’s Hospital in Boston. She and her team have published numerous scientific studies about NIDCAP and, as part of this programme, developed special guidelines for the handling of preterm born and ill babies. They offer NIDCAP courses for professionals who want to improve and develop their neonatal care by following the NIDCAP framework. Currently, there are 24 NIDCAP centres around the globe, with 14 of them in Europe, 6 in the United States, 1 in Canada, and 1 in Australia.

Further information and contacts: www.nidcap.org/en

SAFE®-special for parents of preterm babies

“SAFE®” – an acronym for “secure attachment family education” in German – is an adult prevention programme, derived from the field of attachment research, which promotes safe attachment between parents and baby. This programme was originally developed by Professor Karl Heinz Brisch (Munich University Hospital) and later also modified specifically for parents of preterm born babies. Entitled “SAFE®-special – a special programme for parents of preterm born babies”, this adapted curriculum is designed to accompany the baby’s first 12 months of life. Parents can participate with their preterm born babies starting right after birth. The aim of the programme is to support parents in necessary coping processes, especially with traumatic experiences, as well as to positively influence the attachment between parents and child and their interaction with each other. The programme relies on insights from the field of sensitivity training.

Further information and contacts: www.safe-programm.de

FINE – Family and Infant Neuro-Developmental Education

FINE is an innovative curriculum for family- and child-centred neurological developmental support, which can be adjusted according to the needs of numerous facilities treating preterm and newborn babies. FINE was developed by experts and NIDCAP trainers to narrow the gap between experienced specialists and young professionals as well as medical staff and parents. The programme can be used in every field of neonatal medicine and was developed to help specialists to put theory into practice, to evaluate their own approach, and to plan future steps. FINE is based on three core principles: intensive care has to be performed neuro-protectively, the participation of parents leads to developmental improvements, and every baby has a voice and is treated as an individual. Within the framework of these three principles, FINE organises content and activity around six core themes that cover theory and practice:

- understanding fetal, preterm, and newborn development;
- observing the baby's behavioural signs and adjusting one's own behaviour accordingly;
- understanding and treating parents as equal partners in the care process;
- reflecting on and questioning one's own assumptions and behaviour;
- evaluating and adjusting one's own as well as the neonatal ward's practices based on insights from systems theory and change management; and
- believing that all practice must be rooted in state-of-the-art scientific evidence.

Initial evaluations of FINE show that this programme supports neonatal wards in improving their procedures and encourages medical experts to operate in a more family- and child-centred manner. So far, this international programme has been translated into seven languages.

For further information, please see: www.finetrainguk.com

Important addresses and links



Africa

Parent Organisations

Little Big Souls Ghana

45 Kinshasa Avenue

East Legon Accra

Ghana

Phone: +233 244 336 281

Email: info@LittleBigSouls.org

Internet: www.littlebigsoulsghana.com

African Foundation for Premature Babies & Neonatal Care (AFPNC)

PT 23 APREMDO +233

Takoradi

Ghana

Phone: +233 208 612 000

Email: selina@afpncvoice.org

Internet: www.afpncvoice.org

Preemie Connect

www.facebook.com/preemieconnect

Australia

Parent Organisations

Life's Little Treasures

1/21 Eugene Terrace

Ringwood, VIC 3134

Phone: +61 1300 697 736

Email: us@lifeslittletreasures.org.au

Internet: www.lifeslittletreasures.org.au

Miracle Babies Foundation

PO Box 95

Moorebank NSW 1875

Phone: 24 Hour Family Support 1300 MBABIES / 1300 622 243

Head Office: +61 (0) 2 9724 8999

Email: info@miraclebabies.org.au

Internet: www.miraclebabies.org.au

Preterm Infants Parents' Association (PIPA)

PO Box 400, RBH Post Office, Qld 4029

Phone: +61 1300 Prem Parent (+61 1300 773 672)

Email: contactus@pipa.org.au

Internet: www.pipa.org.au

Healthcare Societies

Australian College of Neonatal Nurses

P.O Box 32

Camperdown

NSW 1450

Phone: +61 (0) 456 645 261

Internet: www.acnn.org.au

Australian Preterm Birth Prevention Alliance

Contact: Richie Hodgson

Phone: +61 (0) 408 128 099

Email: richie.hodgson@wirf.com.au

Internet: www.pretermalliance.com.au

Australasian Neonatal Medicines Formulary (ANMF)

Centre for Big Data Research in Health

Level 2, AGSM Building

UNSW Sydney

NSW 2052, Australia

Phone: +61 (0) 2 9385 9158

Email: anznn@unsw.edu.au

Internet: www.anznn.net

Perinatal Society of Australia and New Zealand (PSANZ)

21/33 Milgate Drive, Mornington

Victoria, Australia 3931

Phone: 1300 867 224 (with-in Australia)

Phone: +61 383 524 221 (overseas)

Email: admin@psanz.com.au

Internet: www.psanz.com.au



Canada

Parent Organisations

Canadian Premature Babies Foundation CPBF-FBPC

4225B Dundas Street West

Etobicoke, ON, M8X 1Y3

Phone: +1 416 418 8916

Contact: Fabiana Bacchini, Executive Director

Email: fabiana@cpbf-fbpc.org

Internet: www.cpb-fbpc.org

Life With A Baby

1136 Centre Street

Suite 409 Thornhill, ON L4J 3M8

Phone: +1 416 833 3860

Email: info@hshf.org

Internet: www.lifewithababy.com

Healthcare Societies

Canadian Association of Neonatal Nurses (CANN)

32 Colonnade Road, Unit 100

Ottawa

Ontario Canada

K2E 7J6

Phone: +1 613 721 7061

Toll Free: +1 888 625 8455

Email info@neonatalcann.ca

Internet: www.neonatalcann.ca

Canadian Neonatal Network (CNN)

MiCare Research Centre

700 University Avenue, Suite 8-500

Toronto, Ontario M5G 1X6

Contact: Priscilla Chan, Coordinator

Phone: +1 416 586 4800 ext 3833

Internet: www.canadianneonatalnetwork.org/portal

Canadian Neonatal Follow-Up Network (CNFUN)

based at BC Children's & Women's Health Centre

4480 Oak Street, Room K3-184

Vancouver, BC V6H 3V4

Phone: +1 604 875 2000 ext 5173

Email: cnfun@cw.bc.ca

Internet: www.cnfun.ca

Canadian Paediatric Society (CPS)

2305 St. Laurent Blvd

Suite 100

Ottawa, ON Canada K1G 4J8

Phone: +1 613 526 9397

Email: info@cps.ca

Internet: www.cps.ca

Children's Healthcare Canada

495 Richmond Road, Suite 102

Ottawa, ON | K2A 4H6

Phone: +1 613 738 4164

Email: info@childrenshealthcarecanada.ca

Internet: www.childrenshealthcarecanada.ca

Ireland

Parent Organisations

Irish Neonatal Health Alliance (INHA)

26 Oak Glen View, Southern Cross, Bray, Co. Wicklow

Phone: +353 (0) 85 1920 602

Email: info@inha.ie

Internet: www.inha.ie

Healthcare Societies

Irish Neonatal Society

9a, Coolkill, Sandyford

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Phone: +353 1 295 8859

Internet: www.irishneonatalociety.ie



New Zealand

Parent Organisations

The Neonatal Trust

PO Box 9366, Marion Square
Wellington 6141
New Zealand
Email: contactus@neonataltrust.org.nz
Internet: www.neonataltrust.org.nz

Healthcare Societies

Australian and New Zealand Neonatal Network (ANZNN)

Centre for Big Data Research in Health
Level 2, AGSM Building
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NSW 2052, Australia
Phone: +61 (0) 2 9385 9158
Email: anznn@unsw.edu.au
Internet: www.anznn.net

Neonatal Nurses College Aotearoa (NNCA)

Internet: www.nzno.org.nz/groups/colleges_sections/colleges/neonatal_nurses_college

New Zealand College of Midwives

376 Manchester Street
St Albans
Christchurch 8014
Phone: +64 (0) 3 377 2732
Internet: www.midwife.org.nz

Perinatal Society of Australia and New Zealand (PSANZ)

21/33 Milgate Drive, Mornington, Victoria, Australia 3931
Phone: 1300 867 224 (with-in Australia)
Phone: +61 3 8352 4221 (overseas)
Email: admin@psanz.com.au
Internet: www.psanz.com.au

United Kingdom

Parent Organisations

Bliss – for babies born premature or sick

Fourth Floor, Maya House
134-138 Borough High Street
London SE1 1LB

Phone: +44 20 7378 1122

Email: ask@bliss.org.uk

Internet: www.bliss.org.uk

Leo's

Registered Charity 1179901
8, Hall Wood Close, Yarm, TS15 9FR
UK

Phone: +44 78 2435 3130

Email: hello@leosneonatal.org

Internet: www.leosneonatal.org

Tiny Life

- The Premature Baby Charity for Northern Ireland

The Arches Centre, 1st Floor
11-13 Bloomfield Avenue
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Phone: +44 (0) 28 9081 5050

Email: info@tinylife.org.uk

Internet: www.tinylife.org.uk

Tommy's

Nicholas House
3 Laurence Pountney Hill
London, EC4R 0BB

Phone: +44 20 7398 3400

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Internet: www.tommys.org



Healthcare Societies

British Association of Perinatal Medicine (BAPM)

5 - 11 Theobald's Road London

London

WC1X 8SH

Phone: +44 20 7092 6085

Email: bapm@rcpch.ac.uk

Internet: www.bapm.org

Neonatal Nurses Association UK (NNA UK)

39 Kirkfield lane, Thorney, Leeds

LS14 3EP

Phone: +44 7578 251 460

Email: admin@nna.org.uk

Internet: www.nna.org.uk

Royal College of Paediatrics and Child Health (RCPCH)

5-11 Theobald's Road

London

WC1X 8SH

Internet: www.rcpch.ac.uk

The Neonatal Society

Contact: General Secretary Prof. Andrew Ewer

Phone: +44 121 627 2686

Email: a.k.ewer@bham.ac.uk

Internet: www.neonatalociety.ac.uk



USA

Parent Organisations

Graham's Foundation

P.O. Box 755

1205 Louisiana Ave

Perrysburg, OH 43552

Phone: +1 888 466 2948

Internet: www.grahamsfoundation.org

Hand to Hold

13740 Research Blvd., Suite L5

Austin, TX 78750

Phone: +1 855 424 6428

Email: kelli@handtohold.org

Internet: www.handtohold.org

NICU Parent Network (NPN)

1999 Main St Ste C-144 Madison, MS 39110

Phone: +1 601 345 1772

Email: connect@nicuparentnetwork.org

Internet: www.nicuparentnetwork.org

Healthcare Societies

Academy of Neonatal Nurses (ANN)

6366 Commerce Boulevard, PMB 357

Rohnert Park, CA 94928

Phone: +1 707 795 2168

Internet: www.academyonline.org

American Academy of Pediatrics – Section on Neonatal Perinatal Medicine (AAP)

National Headquarters

345 Park Boulevard

Itasca, IL 60143

Phone: +1 800 433 9016

Internet: www.aap.org/en/community/aap-sections/sonpm





American Women's Health, Obstetric and Neonatal Nurses (AWHONN)

1800 M Street, NW, Suite 740S

Washington, DC 20036

Phone: +1 800 673 8499

Email: customerservice@awhonn.org

Internet: www.awhonn.org

National Association of Neonatal Nurses (NANN)

8735 W. Higgins Road, Suite 300

Chicago, IL 60631

Phone: +1 800 451 3795

Email: info@nann.org

Internet: www.nann.org

National Association of Neonatal Therapists (NANT)

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Cincinnati, OH 45253-1790

Phone: +1 866 999 5524

Email: info@neonataltherapists.com

Internet: www.neonataltherapists.com

National Association of Perinatal Social Workers (NAPSW)

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Internet: www.napsw.org

National Black Nurses Association (NBNA)

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The Editors



Silke Mader is EFCNI's co-founder as well as Chairwoman of the Executive Board. Prior to this, she was Chairwoman of the German federal association "Das frühgeborene Kind e.V." ("The preterm born child"). Mader is a mother of preterm born twins; one of them died a few days after birth. She is co-editor as well as author and co-author of several renowned scientific and political publications on the topics of maternal and infant health as well as preterm birth. Over the years, Mader has received numerous national and international awards for her work. She is Honorary Lecturer at the School of Nursing and Midwifery, Queen's University Belfast, Northern Ireland. Mader also participates as patient representative in executive boards and supervisory boards. She has been an Ashoka Fellow since 2015. A year later, she received the Bavarian State Medal for Services in the Fields of Health and Long-term Care.



Nicole Thiele joined EFCNI in 2010 and holds the position of Vice Chair of the Executive Board. As the foundation's deputy director, she advocates for improved measures to prevent preterm birth as well as better treatment and care for newborns globally. Thiele is (co-)author and co-editor of various scientific and political publications on public health. She has also developed a variety of educational and information materials for different interest groups. As a patient representative, Thiele works for quality improvement in ante- and neonatal care, patient participation, and fights for preterm born children and their families. Her motivation stems from her own family experiencing the consequences of an extremely preterm birth nearly 50 years ago.

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Professor Dietrich Abeck worked at the dermatological wards of the Munich University Hospital (LMU), the Hamburg University Hospital, and the Technical University of Munich. Since 2003, he has been working in his own practice with a focus on paediatric dermatology. He also works as medical consultant. Abeck is a member of PädExpert's expert group, a platform with the aim to improve access to healthcare in rural regions, and advises paediatricians across Germany on questions of dermatology. He is (co-)editor of several handbooks on paediatric dermatology and co-founded the internet platform www.derma.plus where experts on dermatology write about clinic, diagnoses, and therapies for dermatological diseases, reflecting the current state of the art.



Professor Karl Heinz Brisch specialises in child and adolescent psychiatry and psychotherapy, adult psychiatry and neurology, including psychosomatic medicine, psychoanalysis, trauma psychotherapy, and group psychoanalysis. He was head of the Department of Pediatric Psychosomatic Medicine and Psychotherapy at the Dr von Hauner Children's Hospital at the University of Munich, Germany. Brisch held the first ever Chair in Early Life Care at Paracelsus Medical University in Salzburg, Austria. He also lectures at the Psychoanalytic Institute in Stuttgart, Germany. Brisch's main research and clinical interest is in early child development and attachment psychotherapy in all age groups. He has published numerous books, papers, and articles on attachment development in high-risk infants and clinical attachment research. He developed the prevention programmes "SAFE® – Secure Attachment Family Education" and "B.A.S.E.® – Babywatching" for use in educational and other settings. Brisch is a founding member of the German-speaking Association for Infant Mental Health (GAIMH) and led the organization for many years. His website is: www.khbrisch.de



Dr Till Dresbach is executive senior physician of the neonatal ward and the paediatric intensive care unit at the University Hospital in Bonn. Dresbach is an expert in the fields of paediatric intensive and emergency care as well as paediatric infectiology. He has co-authored various scientific publications and held numerous talks on topics concerning neonatology and infectiology. In 2013, he co-founded the German network www.MRSA-Kinder.net jointly with the DGPI, the German Society for Pediatric Infectious Diseases. The platform provides information about multiple drug resistance (MDR) in children. Dresbach also heads the MDR outpatient department for children and adolescents at the University Hospital in Bonn and founded the project "Kindernotfallbox" ("children's emergency box" in German), a first aid kit designed especially for emergencies involving children.



Monique Oude Reimer-van Kilsdonk is a NIDCAP consultant at the Erasmus MC-Sophia children's hospital in Rotterdam and vice director at the Sophia NIDCAP training centre, also in Rotterdam. In 1992, she began working as paediatric nurse at the neonatal intensive care unit. Two years later, she completed her NIDCAP training in Lund, Sweden, and has been working as NIDCAP trainer herself since 2017. Oude Reimer-van Kilsdonk currently works as expert for the clinical development of neonatal intensive care units. In this capacity, she supports wards in providing individualised care for newborns and their families. Together with Inga Warren, a colleague and experienced NIDCAP trainer from London, she initiated the family- and child-based neurodevelopmental education programme FINE ("Family and Infant Neurodevelopmental Education Programme"). Oude Reimer-van Kilsdonk has also shared her extensive experience in neonatal care in numerous talks and lectures in German, English, and Dutch. Since 2014, she has been a part of the project European Standards of Care for Newborn Health, initiated by EFCNI, and heads the topic expert group on care procedures.



Dr Dieter Sontheimer is a specialist in neuropaediatrics and neonatology. Between 1998 and 2017, he was the chief physician at the children's hospital in Wernigerode and, from 2006 onwards, in Quedlinburg as well. He completed his studies in medicine in Marburg, Berlin, and Heidelberg between 1974 and 1981, and received his doctorate in 1983 from the Institute for Family Therapy in Heidelberg. Sontheimer specialised in paediatrics in the children's hospital in Heidelberg with additional stints in Groningen and Boston where he worked as senior physician until 1998. Sontheimer has authored scientific publications about General Movements and Kangaroo Care. He is also a co-founder of the German federal association "Das frühgeborene Kind e.V." ("The preterm born child") and spokesperson for the association's interdisciplinary working group "Guiding Principles for Developmental Care in Neonatology".



Kerstin Sontheimer was Head Nurse at the neonatal intensive care unit at the Dorothea Christiane Erxleben hospital in Wernigerode between 1999 and 2017. Between 1983 and 2000, she worked there as paediatric nurse. She also interned and then worked at the Children's Hospital in Boston, expanding her professional experiences and specialist knowledge. Sontheimer has authored scientific publications and held talks and lectures on the NIDCAP care model and kangaroo care. She was also an active member of the interdisciplinary working group "Guiding Principles for Developmental Care in Neonatology", organised by the German federal association "Das frühgeborene Kind e.V." ("The preterm born child").



Carmen Walter holds a Master's Degree ("Magister") in Education from the University of Vienna where she specialised in psychoanalysis and education, special needs, and inclusive education. She also holds a Bachelor's Degree with honours in Graphic Design from Staffordshire University. Walter worked as a kindergarten teacher and has additional training in Early Childhood Education from BAKIP Amstetten. She completed her doctoral studies in Human Biology at the LMU University of Munich. Her thesis analysed the long-term attachment development of infants born very preterm from their birth until the age of majority. Between 2014 and 2019, she collaborated extensively with Professor Karl Heinz Brisch, first at the Department of Pediatric Psychosomatics and Psychotherapy at the Dr von Hauner Children's Hospital before moving to the Institute for Early Life Care at Paracelsus Medical University in Salzburg, Austria. She currently works as special pedagogue for children with autism spectrum disorders and developmental disabilities in Vienna.



Dr Inga Warren is an expert in the field of neonatal development. She is a founding member of the Brazelton Centres UK and the UK NIDCAP Centre, which she currently heads as director. Warren has been active as NIDCAP trainer for many years and teaches both medical as well as therapeutical professionals. Warren also initiated the family- and child-based neurodevelopmental education programme FINE ("Family and Infant Neurodevelopmental Education Programme") and co-authored numerous articles and textbooks. Moreover, she contributed to the development of EVIN ("EValuation of INtervention"), the first scale to evaluate the use of widely recommended nonpharmacological strategies to reduce neonatal pain and stress during procedures. Finally retired, Warren wants to use her extensive experience to help the FINE programme succeed internationally and make a lasting impact on neonatal care. Since 2017, she has been an Honorary Research Associate at the University College London Hospitals NHS Foundation Trust. In 2021, she was appointed Commander of the Order of the British Empire (CBE) for her services to preterm babies.

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About EFCNI

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

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